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RESEARCH ARTICLE

Defining preventable birth defects: The March of Dimes' new program of publicity, research fundraising, and advice for pregnant women (1953–1973)

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Argument

This article uses archival material to trace rising rhetoric about prenatal prevention of birth defects. I argue that the new philanthropic framing of "birth defects," aimed to create a coherent category and scientifically prevent a complex array of intractable anatomical and functional disorders seen in infants and young children, with repercussions for women. Emphasis on scientific prevention of birth defects was built on networks of volunteers, fundraising activities, and philanthropic marketing models that had been developed for a crippling epidemic disease, polio. The National Foundation's (NF) expansion to congenital malformations fit uneasily within the prior infectious disease eradication model, assuming that elimination of birth defects was a worthy and achievable goal. Scientific research fundraising, advice, and advocacy aims became entangled. Marketing of birth defects as a vast problem and looming undesirable outcome for all potentially pregnant women was shaped by philanthropic and professional domain expansion. The NF initially promised that funding scientific research innovation would yield a return on investment, with scientific research on pregnancy leading inevitably to elimination or repair of congenital malformations or medical rehabilitation. However, definitions of prenatal prevention were unstable, and prioritizing research and medical aid funds for the vast array of chronic conditions defined as their new target became a challenge. Framing birth defects as a public health crisis, such advocacy leveraged parents' hopes and aspirations for their children's future well-being towards fundraising for medical research and technologically mediated gatekeeping of bodily and functional differences.

Keywords: birth defect; birth anomaly; pregnancy; philanthropy; pediatric; disability

Introduction

This article examines the National Foundation for Infantile Paralysis' (NFIP's) expanded mission to address congenital malformations in addition to poliomyelitis, with an eye to how their framing of birth defects prevention changed in the 1960s and impacted advice intended for pregnant women. It is based on parental advice manuals, published magazine and newspaper articles, and archival material from the March of Dimes Archives, the Children's Bureau, and the Virginia Apgar Papers.[1] Although there are comprehensive literatures on prenatal monitoring and testing technologies, they sometimes narrowly examine prenatal genetic tests as if they had appeared unassisted, obscuring how these technologies were tied to philanthropic research advocacy, along

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[1] The NFIP, founded in 1937–1938, changed its name to the National Foundation (NF) in 1958 when the mission was expanded to include congenital malformations and juvenile arthritis. By 1976, they assumed the name of their fundraising campaign, becoming the March of Dimes Birth Defects Foundation.

with medical specialization and professional advancement. Despite debates about whether prenatal testing is eugenic, there has not been adequate articulation of how eugenic characterizations of fitness changed as birth defects emerged as an important target for scientific, medical, and public health intervention (Rapp 1987; Rothman 1986; Cowan 2008; Löwy 2017).[2] In particular, I show how the National Foundation (NF), along with obstetric anesthesiologist Virginia Apgar as the Director of the Division of Congenital Malformation, flattened the complexity of birth outcomes when they popularized the term "birth defects." This evolving medico-scientific vision of birth defect prevention portrayed birth defects as something common that could happen to any (married) woman, even as the techniques and rhetoric about prevention changed and became more focused on individual autonomy over utilitarian justifications.

The objective of the NF—which combined a moral and medical mission with a scientific fundraising effort—was to portray anomalous infants as a neglected public health crisis and spread word about the risks of infant disability to a wider audience (Altenbaugh 2015, 60–61, 65–66; Ettling 1981; Tomes 1998).[3] In order to inform the public about severe "crippling" conditions like spina bifida, midcentury medical and philanthropic leaders wanted to move away from potentially unpleasant or medical terms like "monsters" or "malformations." They therefore framed their new program broadly, calling infant anomalies "birth defects." Internal documents from the March of Dimes demonstrate their deliberations about the entangled goals of publicizing the scientific prevention of birth defects, fundraising for medical and scientific research, destigmatizing congenital malformations, and rehabilitating those born with physical impairments. I argue that publicity about birth defect prevention in the late 1950s and 1960s simplified an incredibly complex array of congenital impairments, portrayed them as a common and preventable problem, and initially promised their erasure through scientific research and technoscientific progress.

The postwar period saw a professional reevaluation of eugenic goals and language about the supposedly unfit and considerable parental advocacy for impaired children in the U.S. For instance, the National Association for Retarded Children (NARC), formed in 1953 (Ladd-Taylor 2017, 187–188). Some of the NF's language and approach to disability was consistent with eugenic language, and the goal of improving population quality by encouraging healthy reproduction, even as they did not specifically target families with genetic illnesses or undesirable hereditary characteristics (D.B. Paul 1995, 143; Kevles 1995; Pernick 1996; Wellerstein 2011, 45–46; Comfort 2012; Stern 2016).[4] My interest is less in eugenics or the institutional transformation required to shift from polio to birth defects, but in what this new framing of congenital malformations implied about advice intended for women. Indeed, all women who might become pregnant were framed as

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[2] Prenatal screening and ultrasound technologies developed in the 1960s ushered in the era of "tentative pregnancies," with women and their doctors as "moral pioneers" in the 1970s and 1980s. First directed at Down syndrome and hemophilia, it then expanded to other chromosomal aneuploidies and Mendelian genetic illnesses (and in the 2000s, deletion syndromes).

[3] A number of scholars note religious undertones in early-twentieth-century infectious disease campaigns. The National Tuberculosis Association (NTA), among others, combined advertising and health education, much like the NFIP.

[4] Diane Paul and Alex Wellerstein describe the term "eugenics" as chameleon-like, with indeterminate meaning but nasty connotations. In pejorative usage, it refers to the coercive exclusion, elimination, or reproductive control of people considered to have undesirable hereditary characteristics (or, conversely, encouraging the reproduction of those thought particularly high achieving), influenced by agricultural breeding models, sometimes with explicitly elitist or racist agendas. However, historians have demonstrated that a broad and malleable notion of heredity was used to support a wide range of eugenic approaches during its peak popularity in the early twentieth century. There were certainly pseudoscientific early 1900s studies of inherited alcoholism, criminality, or depravity, like the Jukes or Kallikaks, but in popular use it could be a synonym for good parenting, and there were also reformers using the language of eugenics to support marriage laws, improved nutrition, labor reforms, and social services to produce "good births," which were not out of line with the NF's medically focused program. Some have compared eugenics to an umbrella, which, when closed (i.e., defined narrowly) shares little overlap with contemporary efforts, but which, when fully expanded is analogous to many social movements pertaining to reproduction, families, disability, and social welfare. Furthermore, several accounts highlight continuities with medical genetics, moderated by greater attention to patient autonomy and less confidence in state-sponsored collectivist solutions.

at risk for infant anomalies, and promises about progress and a return on scientific investment were tied to calls for maternal vigilance.

A longstanding feminist critique argues that medical tools of observation and attention to fetal patienthood increased surveillance of pregnancy, even as they obscured or diminished attention to maternal sensations or wellbeing, rendering women as empty vessels for reproduction, or potentially pregnant mothers-in-waiting (Warin and Martin 2018; Petchesky 1987; Duden 1993; Martin 1988). In spite of the apparent midcentury reliance of medical research on white men, and the foundational genetics premise that men and women contribute equally to reproduction, there is no medical specialty dedicated to male reproductive health, and attention to male reproductive outcomes was rare before the 1980s (Daniels 2006; Almeling 2020; Epstein 2007). Concerns about reproduction typically centered on women, even as knowledge about health effects was sometimes limited by their exclusion from research studies (Waggoner and Lyerly 2022; Almeling 2020). Salim Al-Gailani and Miranda Waggoner have independently traced women's preconception care during the "zero trimester" as an emergent market-driven panacea for healthy pregnancies, birth outcomes, and citizenship (Al-Gailani 2014; Waggoner 2017). The antecedents to preconception care lie in the reproductive concerns of eugenicists, particularly about syphilis, and new attention to birth defects that arose in the 1950s and early 1960s, linked to thalidomide exposure, rubella epidemics, and later folic acid supplementation (Reagan 2010; Al-Gailani 2014; Waggoner 2017).

Debates continue about the relevance of eugenic policies to contemporary carrier or reproductive genetic screening, although there tends to be greater consensus about screening for conditions that either typically cause pain or death in early childhood (e.g., Tay Sachs, anencephaly) or for which there are effective treatment approaches (e.g., phenylketonuria, or PKU) (e.g., Parens and Asch 2003; Dive and Newson 2022). Despite the near universality of experiences of disability and debility, visions of a desirable future were often linked to notions of an able or capable body (Kafer 2013). The role of caregivers, and their attendant trials and joys caring for children or the severely disabled in a context where medical care is privatized and care work is gendered and racialized, remain central to these debates (Kittay 2011; Reagan 2010). Ruth Schwartz Cowan has argued that because families with inherited illness had a role in the development of prenatal genetic testing, it was not eugenic but rather enabled reproductive autonomy and family creation (Cowan 1994, 2008). Justly highlighting women's agency and the shift from coercive state practices towards greater attention to parental autonomy, she does not underscore how extensively the marketing of birth defects, as a looming problem for all expectant women, was tied to philanthropy and medical research.

Science studies scholars contextualize biopolitical discourses about preconception and prenatal care within "anticipatory regimes" that project future risks to as-yet-unconceived fetuses (Waggoner 2017, 25; Adams, Murphy, and Clarke 2009). These discourses about future risks are inherently linked to growth and specialization within biomedicine, particularly the expanding medical domains of obstetrics, gynecology, and pediatrics, but also the ambivalent concerns of geneticists, radiobiologists, or teratologists (Halpern 1988; Frickel 2004; Creager 2016; Dron 2016). This could be seen as the inception of what political scientist Jennifer Denbow characterizes as the ascendency of genetics and the contemporary state's role in speculative biotechnical capital accumulation, which is often obscured even as it abets the construction of a self-regulating risk-averse pregnant subject (Denbow 2020). This article seeks to contribute to the history of reproductive health, linking the histories of eugenics, gender, disability, and reproductive justice. It exposes the connections between the reframing of birth defects and philanthropical and professional domain expansion, showing how, in the context of the relative neglect or even involuntary sterilization of women of color, this reframing initially enlisted primarily married middle class White women to create "well born" productive citizens (in part, perhaps, because women were presumed to be the inevitable caregivers of children, especially those with severe disabilities).[5]

In the NF's case, the rhetoric and publicity it had used to combat epidemic polio proved an uneasy fit for preventing diverse and chronic birth defects during the prenatal period, and pregnant women remained in the crosshairs of the new approach. Simplistically, eliminating genes and maldevelopment proved even more difficult than eradicating germs, which ensured long-term program viability. Publicity about birth defects portrayed them as a pressing public health crisis and facilitated a transition away from a paternalistic narrative about the exceptional rarity of congenital malformations. Instead, it implied that they were not infrequent, urging women to be wary medical consumers, responsibly taking action to avoid birth defects (publicity rarely acknowledged that this was not always possible). While preventing children's suffering might seem a worthy goal, emphasis on prenatal prevention could also undercut the goal of reducing societal intolerance, imply that cognitive or anatomical differences inevitably caused suffering, and de-emphasize the needs of children after they grew to adulthood.[6] In any case, this emphasis certainly had profound implications for advice to and care of pregnant women in the latter half of the twentieth century.

When the NF took on congenital malformations as part of their Expanded Program in 1958, it promulgated a medical vision of childhood impairments that had become common in the 1950s. If infants born with unusual anatomy had previously been seen as omens, wonders, or playful tricks of nature, by the early twentieth century such infants were typically interpreted as deviations from normal development (Daston and Park 1998; Wilson 1993; Rich 2019).[7] Internal documents from the March of Dimes archives exhibit some self-awareness about the complexity of their new mission of addressing chronic conditions rather than epidemic illness. Nevertheless, the Foundation's experience with paralytic childhood polio meant that, from the outset, they tended see birth defects through that lens of paralysis even as they grouped both mild and severe bodily differences together into one overarching statistic in their upbeat messaging about vanquishing birth defects. They asserted hopeful ideals, assuming that medicine could mend and rehabilitate children born with disabilities, helping them overcome their disability, and promoted a vision of prenatal prevention of birth defects through women's behavioral modification, medical technologies, and medical care during pregnancy.[8] If initially they tended to highlight prevention

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[5] A number of scholars have identified how reproductive care for Black women changed before and after emancipation. In the "afterlife of slavery," Black women's fertility stopped representing a net economic boon to White slave owners and, by the mid-twentieth century, became a target for eugenicist intervention—even as the eugenics movement waned. The criminalization of substance abuse, punitive use of child welfare legislation during pregnancy, neglect of post-partum maternal health, and application of involuntary sterilization in the twentieth century have also differentially impacted low-income women of color in a context where fears about the fertility of non-White groups in the U.S. undermined the broad application of pronatalist policies that supported parents, such as paid time off or childcare (Roberts 1997; Cooper Owens 2017; Lira 2022; Davis 2019; Kandall 1996; Briggs 2017).

[6] A variation of the medical vs. social model of disability critique, in which disability is a porous state mediated by the built environment, societal context, and stigma rather than a fixed bodily inadequacy.

[7] Maternal impressions and marked children remained a concern, at least for laypeople, through the early twentieth century (Wilson 2002). While purportedly an objective statistical standard, "normal" was used in diverse context-specific ways and is often compared to "subnormal," rather than a statistical outlier above average. Moreover, the term frequently implied a moral quality, a gap between "is" and "ought" (Baynton 2001, 52). Likewise, bodies that deviated from heteronormative White male middle class norms were more frequently labeled as disabled or pathological, demonstrating routine conflation of socioeconomic status, disability and race or ethnicity (Almeling 2020, 10; Schweik 2009).

[8] I am acutely aware of how the state and experts have defined and circumscribed the lives of people with disabilities, how the medical model portrays disability as individual bodily flaws, and how explicit and implicit biases are sedimented into disability labels that justify inequality and exclusion from certain benefits and rights of citizenship (Baynton 2001; Carey 2009). Medical approaches that emphasize either fixing or preventing disabilities have been called the "cure or kill" approach (e.g., by Rosemarie Garland-Thomson 2001, 355). Nevertheless, I sometimes use terms that readers may find offensive to convey what, at the time, was likely considered neutral technical terminology in order to show how congenital anomalies were framed in the 1950s.

through vaccines, vitamins, or other medical therapies (such rubella vaccination, transfusions in instances of differing maternal and fetal rh-factor blood type, or a modified diet to prevent the intellectual disabilities of the metabolic disorder PKU), by the 1970s prevention was expanded to include prenatal diagnosis and the potential termination of affected pregnancies.

As Leslie Reagan shows, U.S. state abortion laws were under scrutiny from the late 1950s by reformers who wanted to narrowly expand the rights to certain classes of abortions. In some states it was routine for upper-class women to obtain "therapeutic" abortions for indications like rubella infection, if approved by a panel of physicians, and those with the means and connections even traveled to countries like Sweden to have the procedure performed (Reagan 2010, 58–59, 85–88, 139–144). Even if medical abortion for presumed fetal anomaly was part of medical practice, the transition from eliminating a virus to eliminating fetuses likely to have a disability was not entirely comfortable for the organization, and their rhetoric about birth defects and prenatal prevention changed considerably by the early 1970s.

Virginia Apgar and the NF contributed to the project of informing the public about birth defect prevention. This was based on a model of philanthropic mobilization used to address polio epidemics, which included raising research funds by highlighting curative scientific innovation, grants for acute care, and rehabilitation for those who suffered paralysis or other disabling effects. Several failed vaccine trials in the 1930s redirected attention to fundamental immunology and virology research (Halpern 2004). Scientists heatedly debated the merits of different approaches to polio vaccine development and testing, particularly strain choice, routes of infection, the ease of use, longevity, safety, and efficacy of vaccines based on live or killed virus, and whether trials should be observational or controlled (Rogers 1992, 176–182; Paul 1971). Too hastily for scientists and administrators alarmed by prior vaccine trial failures, who wanted further investment to better understand polio strains, infection, and routes of transmission, the NF supported national trials of Jonas Salk's killed-virus vaccine (Halpern 2004, 41–67; Paul 1971).[9] This vaccine relied on John Ender's tissue culture techniques and was developed and tested first on Pittsburgh lab staff, and then on institutionalized handicapped youth and schoolchildren between 1952–1954 (Gallagher 1985; Smith 1990, 120–206; Rogers 1992, 176–182; Oshinsky 2005; Altenbaugh 2015).

By 1954, the NF was portraying polio epidemics as on the cusp of eradication, and contributions began to drop even before final trial results were announced in 1955 (Smith 1990, 301). Given their apparent success targeting polio and anticipated declines in volunteers and contributions, the NF made assumptions common to their era about what would mobilize their volunteers and helped redefine, while sometimes circumscribing, those thought capable of rehabilitation. Initially, they focused on children with central nervous system handicaps that caused paralysis or impaired mobility, said little about intellectual disability, and largely portrayed European American children in their campaign materials (Mawdsley 2010; Altenbaugh 2015, 31, 70–71).[10]

To illustrate NF efforts to consolidate diverse neonatal anomalies into a target for scientific research fundraising and advocacy amidst evolving approaches to diagnosis and prevention, I will first examine how the term "birth defects" was defined and used in lieu of terms like congenital malformations, monsters, or "defective" infants. Those who did so were trying, not entirely successfully, to shake the stigma long associated with atypical bodies and function, which could be seen as an influential antecedent to the disability rights movement (Altenbaugh 2015, 191;

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[9] Sydney Halpern analyses the moral reasoning surrounding the failed trials of two vaccines developed by William Park, Maurice Brodie and John Kolmer 1934–1935. Virologist John Paul's insider history also highlights differing scientific perspectives regarding further research on polio virology and expediated vaccine testing—it is worth noting that some scientists wanted to roll out vaccines even more rapidly, in observational rather than controlled trials, and that vaccine trials in institutionalized children were justified because of their baseline high rates of infectious disease.

[10] Racial integration was complex; initially chapters were segregated and there were specialized fundraising materials and hospitals, but internal advocacy by Charles H. Bynum (1944–1954) ensured that some African Americans could access acute polio care in predominantly White hospitals.

Gallagher 1985, 145–150).[11] I will then discuss the NF's decision to shift their mission from polio to congenital malformations and how their rhetoric about prevention changed as prenatal diagnosis and selective termination became available for some families, facilitated by rising interest in women's bodily autonomy. Influenced by these changes, they modified language about eliminating birth defects and refocused on maternal and child wellbeing and parental autonomy rather than societal benefit. Finally, I will backtrack to explore how the thalidomide disaster buoyed the NF's Expanded Program by widely publicizing infant disability and building intense public interest in pharmaceutical and other environmental factors affecting prenatal development. Thalidomide influenced and augmented the NF's publicity, even as their scientific research funding helped to launch careers in medical genetics and raise particular concerns about the drugs and other substances women consumed.

Defining birth defects: Foundations, experts, and popular media

The 1950s witnessed renewed scientific and medical interest in abnormal human development and the prenatal period during a period of demographic expansion. With reduction in childhood mortality from infectious disease, rising birth rates, and a higher proportion of hospital births, congenital malformations loomed larger as a cause of childhood morbidity and mortality (Saffian 1962, 5–7).[12] Nearly all births (greater than 80%) occurred in hospital settings, so congenital malformations were the object of medical and state attention rather than the private experience and care of individual families and birth attendants. Physician scientists at the time portrayed congenital malformations as something previously shunned, hidden, or neglected and remarked on the improved ability to diagnose (and often surgically repair) infants born with anatomical anomalies (Warkany 1957).[13]

Birth anomalies in the early twentieth century were largely hidden from public view. Indeed, the legitimacy of reproductive science was contested, in part because of associations with sexuality and women's health (Clarke, 1998, 1991). Social movements of the early twentieth century influenced pediatrics and obstetric professional specialization more than the innovation-driven organ-focused specialties formed in the nineteenth century (Halpern 1988). Gradually, researchers such as perinatal pathologist Edith Potter exposed causes of infant mortality, and others studied maternal undernutrition (Potter and Adair 1940; Buklijas 2014). Josef Warkany showed nutritional factors fundamental to rat development in the 1940s, influencing the NF and also initiated a meeting of like-minded scientists interested in abnormal fetal development in 1956—what would become the Teratology Society (Warkany and Nelson 1940; Dron 2016). Clinicians did not always acknowledge how investment in radiobiology safety research and public fears about deployment and testing of atomic weaponry postwar raised new concerns about reproduction and genetically or developmentally impaired children (Plummer 1952, 36–43; Hollaender 1954; Beatty 1991; Lindee 1994; Rasmussen 1997; Zaretsky 2018; Nemec and Dron 2022; Creager 2015). There was concomitant growth in medical and scientific research fields studying congenital malformations (among them teratology, pediatrics, and later dysmorphology,

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[11] Gallagher and Altenbaugh make this argument, linking the rise of the disability rights movement to polio and the NF's public campaigns, longer life expectancies, and the morbidities of World War II.

[12] Children's Bureau (CB) records indicate that the rate of hospital births in the US increased from roughly 37% in 1935 to nearly 80% of births in 1945. Edward E. Schwartz to Will, Folsom and Smith, Inc. 17 June 1947 Folder 4-6-2-3, Box 104, CB Subject Files [RG102.2], NARA, College Park. The CB administered the crippled children's program from 1935, part of social security. In 1962, reportedly the number of children they served born with congenital malformations had increased from roughly 44,000 in 1950 to nearly 100,000 with congenital malformations in 1960.

[13] "Medical diagnostic procedures such as auscultation, roentgenographic examination, uroscopy or ophthalmoscopy can reveal additional internal malformations, but these often remain unrecognized until illness leads to special examinations" (Warkany 1957, 728).

perinatology, and medical genetics), which helped guide the reorganization of philanthropic organizations and government towards the science-based prevention of birth defects.

In the early 1950s, before the NFIP's new mission, another New York-based charity called the Association for the Aid of Crippled Children (AACC) began to emphasize research pertaining to the prenatal period in addition to training and support for affected children and families.[14] In June 1952, the AACC funded a conference in New York, chaired by an obstetrician and two pediatricians, Emmett Holt, Jr., Theodore Ingalls, and Louis Hellman, addressing "Prematurity, Congenital Malformation, and Birth Injury" (1953). Hellman, a birth control advocate, was subsequently chairman of the Human Embryology and Development Study Section, established at the National Institutes of Health (NIH) in 1954 (Holt 1953). In 1953, Congress also appropriated funds for large studies to understand the association between adverse birth events and cerebral palsy, based on the John Hopkins University epidemiologist Abraham Lilienfeld's studies of the "the continuum of reproductive wastage," suggesting that empirical research on pregnancy was attracting attention and funds in many sectors (Lilienfeld and Parkhurst 1951; Klebanoff 2009).

Professional and philanthropic organizing to fund medical research influenced parenting advice. Holt and journalist Joan Gould published a pamphlet in 1958, partially funded by the AACC, which emphasized the question "Will My Baby be Born Normal?" (Gould 1958). Holt and Gould wanted to make readers more aware of various risks that a pregnant woman might face that could harm the fetus. As such, the pamphlet broaches the issue of babies with different mental or physical characteristics from the norm, highlighting the opportunities for intervention and the responsibilities of pregnant women. They admonished that, "A woman must safeguard her child from the very moment when the child is conceived, and especially during those crucial first months in the uterus … She should know all she can know about safeguarding her baby before she becomes pregnant" (Ibid, 4). Defining eugenics as "encouraging healthy and intelligent people to have as many babies as they want," the pamphlet's emphasis was on women's proactive preconception knowledge and vigilance (Ibid, 16). Notably, this pamphlet lists the American Eugenics Society alongside the NARC, the National Society for Crippled Children and Adults, and the NF as places to seek further advice and resources, showing the overlapping aims of these organizations in the 1950s.

In the context of growing medical interest in prenatal injury and maldevelopment, the National Foundation popularized the term "birth defect." They wanted to form a multiplicity of diverse conditions with wide-ranging etiologies into a single cohesive field, and to make that field intelligible to parents without expert training. Medical terminology typically referred to congenital malformations or congenital anomalies or abnormalities, overlapping definitions that encompassed both obvious anatomical abnormalities visible at birth and more subtle deviations from the norm that became evident as an infant or young child grew. As Martin Pernick's work shows, physicians were tasked with drawing lines defining when rehabilitation was medically possible or desirable for severely affected infants, engaging in vigorous early-twentieth-century debates about withholding treatment, or, more rarely, hastening death (Pernick 1996, 18, 41–55, 81–86).[15] Used infrequently before the 1950s, the term birth defect was reportedly coined by NF publicist Dorothy Ducas and was likely intended to soften prior technical terms for children with serious disabilities, such as "defectives," and "deformed" or "defective" infants (Rose 2016, 128).[16] Nevertheless, changing the terminology did not remove value judgements, and ensuing publicity and news articles about birth defects frequently portrayed a dichotomy between newborns as

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[14] Association for the Aid of Crippled Children, University Committee on Research in Congenital Malformations, Prematurity and Birth Injuries, "Plan" January 1955. Box 1, Folder 1, Series 1.1, Records of the Teratology Society (RTS), The College of Physicians of Philadelphia.

[15] Pernick highlights the persistent malleability of heredity in the early twentieth century and how popular interpretations shaped eugenics.

[16] In a rare prior use, an LA health columnist argued that there "is no hard and set rule for the normalizing of birth defects," despite the "high-pressure salesmanship of an enterprising surgeon" (Lovell 1931, 22).

either blessings or tragedies, collapsing the considerable range of possible birth outcomes and parental reactions (e.g., Baker 1962).

As the NF's Director of the Division of Congenital Malformations, Virginia Apgar helped to shape their publicity and scientific agenda. The Austrian pediatrician and teratologist Josef Warkany influenced the National Foundation's focus on congenital malformations but declined to leave Cincinnati to take a leadership position; Apgar assumed this role. Apgar trained as a surgeon in New York, before specializing in obstetric anesthesiology, and is most famous for creating a widely-used scoring system to assess neonatal vitality (Apgar 1953).

Apgar's writing demonstrates her effort on behalf of the NF and other midcentury researchers to create a coherent and intelligible scientific research and advocacy arena out of seemingly rare, intractable, and diverse infant conditions. The term "birth defect" might thus include both relatively minor anatomical issues, such as webbed toes and cleft lips or palates, or vastly more severe or disabling conditions including errors of metabolism that affected intellectual ability, such as PKU, as well as severe neural tube defects typically incompatible with life, like anencephaly. If the NF initially estimated there were over 600 birth defects, the Children's Bureau Crippled Children's Program tracked the incidence of only six congenital malformations in the 1950s: spina bifida and meningocele, congenital cataract, malformations of the circulatory system, cleft palate and harelip, dislocation of the hip, and clubfoot or flatfoot. In a report from 1962, they emphasized the increasing numbers of children covered by their programs, augmented possibly by "congenital conditions for which medical or surgical care formerly was not available or feasible" (Saffian 1962, 7,18). Despite this apparent medical progress, congenital malformations were portrayed as a growing problem affecting the public purse.

The term "birth defect" could be difficult to parse, in that it could be a more or less inclusive definition depending on how, and by whom, it was wielded. Part of the utility of the term was its very capaciousness, as it shifted attention away from a medical definition rooted in severe anatomical differences towards a broader and more all-encompassing and flexible category that affected more infants (not unlike the term "disability"). Researchers studying teratology were often pragmatically inclined to use the narrower term "congenital malformations," including anatomical abnormalities or functional deficit visible at or shortly after birth. However, this was contested, and even as it lost ground to the broader and more colloquial "birth defects", the term "congenital malformation" was sometimes expanded in the 1960s to include more minor conditions, metabolic malfunctions that affected development, intellectual or behavioral deviations from normal, or functional syndromes that manifested themselves later in childhood.[17]

From infantile paralysis to "crippling" birth defects: The National Foundation's expanded program of 1958

Appeals for contributions to birth defect research were guided by Basil O'Connor, a law partner and advisor to Franklin Delano Roosevelt (FDR), who had helped found the NFIP in 1937–1938. He was a New York-based corporate lawyer whom FDR had tasked in the 1920s with raising funds to support a crumbling resort and polio rehabilitation center in Warm Springs, Georgia. O'Connor demonstrated an aptitude for fundraising, selling a populist vision of soliciting small contributions to address epidemic polio, at times alarming scientists with his flamboyant publicity and bold statements about the imminent and inevitable cure for polio (Paul 1971).[18] Initially, fundraising relied on birthday balls and galas, but later the March of Dimes collected

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[17] In the late 1960s, groups debated how narrowly to define teratogen and congenital malformation for the purposes of pharmaceutical testing. See the 1967 WHO definition of congenital malformations, or *Science* accusation that Dow chemists were trying to redefine teratogenic effects (World Health Organization 1967; Wade 1972).

[18] Virologist and NF grantee John Paul highlighted significant scientific understanding of polio that predated the NFIP. Nevertheless, despite the efforts of organizations like the NTA, it is the NFIP that Paul credits with innovating the approach of

contributions through vast networks of volunteers, more than 3,100 county chapters, myriad mother's marches conducting door-to-door campaigns, and celebrity endorsements and solicitations in movie theaters and other media. Businessmen who wanted political favor, like Henry L. Doherty, helped sponsor elite dinner dances at the Hotel Astor and Waldorf-Astoria in New York City, and lavish parties in towns across America, under the tagline "dancing that others may walk."[19] The vaudeville performer Eddie Cantor coined the March of Dimes fundraising campaign as a play on a popular news series called *The March of Time,* and his 1937 request for dimes to be sent to the President to combat polio initially buried White House mail under a flood of donated dimes—more than 80,000 letters (Altenbaugh 2015, 64–65; Rose 2016, 93–94; Smith 1990, 74).

By the mid-1950s, the administration of NFIP engaged in soul-searching about their mission. With successful vaccine trials, polio seemed vanquished, and they were preparing to expand their focus. As early as 1953, when news of promising vaccine candidates leaked, O'Connor tasked Melvin Glasser (a social worker formerly employed by the American Red Cross) to consider their changing course (Baghdady and Maddock 2008). Glasser appeared receptive to the AACC's interest in funding scientific efforts to prevent infant injury, lunching and corresponding with Leonard Mayo, the AACC's Director (Mayo 1957).

Despite their obvious affinity for childhood conditions, the NFIP considered many options: geriatrics, mental health, viral diseases, muscular dystrophy, maternal and child health, arthritis, diseases of the central nervous system, the common cold, dental health, and juvenile delinquency.[20] Any new program would have to address a compelling issue that would maintain the grassroots appeal and volunteerism associated with childhood polio.[21] Additionally, it would have to be a broader program than polio—a health issue that affected different social strata and regions—in order to build on the donation model of small gifts and a broad base of contributions (Baghdady and Maddock 2008, 62).

As part of this reassessment, the NFIP leadership commissioned a study between 1953 and 1956 from researchers at the Princeton-based American Institute of Public Opinion (founders of the Gallup poll) and at Columbia University's Bureau of Applied Social Research. By surveying the public and interviewing local chapter leaders and volunteers, they hoped to identify what was known about the NFIP, as well as areas of exceptional success or potential improvement (Sills 1957).[22] Gallup and Columbia University specialists recommended an approach that built on NFIP's reservoir of public goodwill and emphasized helping children over approaches that were primarily oriented towards training professionals or mobilizing volunteers. In addition, the social scientists recommended underscoring science as a source of hope, noting that "hope for eventual solution by scientific research is an important ingredient," and that "a future program might well be handicapped if … hope and the possibilities of science did not play a part."[23] Melvin Glasser wrote to Basil O'Connor in 1954 that contributions were often based on "fantasy hope," which was essential to a successful program. Any program would need to have "the promise that someday,

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using small financial contributions to support research seeking to banish disease, noting that their approach seemed to be "money first, ideas about polio afterward" (Paul 1971, 309).

[19] "Birthday Balls: Franklin D. Roosevelt and the March of Dimes." Franklin D. Roosevelt Presidential Library and Museum, http://docs.fdrlibrary.marist.edu/bdayb1.html.

[20] NF, "Approved Program [Booklet]," pp 10, March 20, 1958, Box 6, Folder of same name, MPR, MDA.

[21] By the 1950s a vast network of volunteers at local branches of the March of Dimes was raising funds for polio treatment, research, and training, with patient care consuming most of their funds. Between 1938–1958, NFIP raised more than $489 million, spending $34.2 million on research, $316.2 million on patient care, $35.2 million on professional education, $39.3 million on medical services, and $21.2 million on administration (Hutchings 1958).

[22] Paul K. Perry and Arthur L. Keiser led the project at the Institute, and sociologist David Sills wrote up a monograph. David Sills, "Gallup-Columbia Study on the National Foundation 1953–1956," Box 7, Folder of same name, Series 6, Medical Program Records (MPR), March of Dimes Archives (MDA).

[23] Ibid, 2–3.

regardless of how far in the future, research could eliminate or greatly reduce the problem. If there is even slight promise of this … 'fantasy hope' will take care of the rest."[24] One can see here an effort to take certain aspects of religious life—faith, hope, or salvation—and harness them to secular scientific medical research projects. Part of the success of the fundraising campaign rested on the NF's ability to convey hope that investment in scientific research would, in the future, eventually significantly impact or vanquish congenital disability.

Eschewing the medical language of congenital malformations or the mysticism of monsters or marked children, NF staff used the terminology "defects" and the language of hope and rights to explain their mission of preventable birth defects. Nevertheless, they borrowed eugenic rhetoric, such as the "right to be well born," used by the progressive-era reformers like Jane Addams to laude eugenics research and marriage policies (well born is one translation of the Greek word *eugenes*) (Lombardo 2017, 218–221).[25]

While defining the Expanded Program, staff members considered factors that would affect its success. They chose a broad topic, which would have high impact and the potential to attract and retain the volunteers and grassroots funding they had developed for polio research and rehabilitation. Foundation staff argued that nearly everyone had known polio victims.[26] Would citizens participate in activities associated with congenital malformation? They worried that congenital malformations would be too disturbing to engage their intended audience. Though public awareness *would* increase giving, they noted that the "fear" angle should be handled carefully, as "it obviously would be questionable public service if every potential mother were made to fear that she might have a deformed child." The idea of "malformations and monsters and so on" was "undoubtedly unpleasant to the average person." Yet, the coin could "be reversed, and the idea of assuring more nearly perfect children—children bearing no legacy of defect—could be made positive and attractive."[27] To retain public interest, including volunteers and monetary contributions, they wanted to frame congenital malformations broadly, in a positive and proactive light.

One strong argument against choosing congenital malformations as a mission was that they would need to "reject patient care for the largest number of children who have congenital malformations—namely those with mental deficiencies and with multiple malformations now beyond the knowledge and treatment skill of the medical profession."[28] Staff expressed dismay that for years to come the NF would need to reject the claims of some of the most severely impaired. The issue of how to prioritize research and medical funds for the vast expanse of childhood impairment they defined as their new mission would remain a lingering concern. Even as triumphant stories highlighting the successful surgical repair of infants born with malformations made headlines in the 1950s and 1960s, increased expenditures in Children's Bureau programs hinted that medical intervention sometimes saved lives without restoring typical function (Anonymous 1953, 1960a, 1960b; Milhorat 1974).

Though inspired by the prospect of helping children with "crippling" disorders, the NF's new expanded program, announced in July 1958, was deliberately broad and not tied to a particular

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[24] Melvin A. Glasser to Basil O'Connor, "Memorandum," November 22, 1954, p 2, Box 6, Folder: "Gallup-Columbia University Study on the National Foundation (David Sills) 1953–1956," MPR, MDA.

[25] Eugenic marriage to "stem the propagation of defectives," prompted requirements for medical certificates before marriage, first enacted in 1909 in Washington state (Lombardo 2017, 220–221). Despite resistance to obligatory medical examination of women, by the 1930s prohibitions on marriage of people infected by venereal disease existed in twenty-six states and a 1935 Connecticut law required syphilis blood testing and medical exams before marriage for both sexes (Brandt 1985, 147).

[26] David Sills recorded that just over half of the public surveyed reported knowing a polio victim (Sills 1957, 128).

[27] NFIP, "Proposed Program: Congenital Malformations, 1957," 32–33, Box 6, Folder of the same name, MPR, MDA; Joseph Mori, "Essay on the Meaning of the National Foundation's New Program—Retrospective and Prospective," 4, Box 6, Folder of the same name, MPR, MDA.

[28] NFIP, "Proposed Program: Congenital Malformations, 1957" 32–33, Box 6, Folder of same name, MPR, MDA.

disease, encompassing the field of congenital malformations, juvenile arthritis, and polio. In publicity, O'Connor outlined the aim of establishing the total number of children affected by juvenile arthritis and "to start at once to find children who have defects which can be corrected or improved."[29] He argued that birth defects were the "largest unmet childhood medical problem in the United States."[30]

Though NF staff knew that the birth of infants with unusual anatomy was an old and seemingly intractable problem, they may have underestimated the complexity of congenital disability. Research on birth defects could be interpreted to mean both therapeutic and basic science questions related to a diverse range of disorders, though they specifically excluded cardiac conditions (the purview of other foundations). The NF was interested in funding both biological processes and studies in rehabilitation, including viral and radiation research, genetics, pharmacology, and studies of causes and prevention.[31] In this new project, the prenatal period was of particular concern, as science "was just entering the era where we are learning what causes damage to the embryo," and it was too early to say that "chemical means cannot be discovered for protecting the unborn child within its mother" (the phrasing implies this was thought unlikely). Evoking concerns about atomic energy, *in utero* radiation is also listed as an area of research and a cause of birth defects: "Any radiation may damage human germ cells and result in the birth of children with defects."[32]

The Expanded Program was launched at a televised press conference at the Waldorf-Astoria Hotel in New York City in July 1958, with speeches by well-known scientists, among them NFIP grantee and polio vaccine investigator, Jonas Salk. NF President and co-founder, Basil O'Connor, emphasized the new program's scientific grounding and flexibility (Whitman 1972). O'Connor prepared to answer a range of anticipated questions about the breadth and objectives of the program: Was the prevention of birth defects effectively a matter of "birth control"? What could be done for infants with impairment of the central nervous system? Was the program so broad that it was "a blank check to do whatever you choose?"[33]

Most public reactions to the expanded program were laudatory, a testament to the widespread excitement about the potential of applied scientific research in the 1950s and public support for the objectives of the NF. Like many health initiatives, their language evoked fighting or a military campaign (Rose 2016, 85–102).[34] The *New York Times* declared that: "The brilliant history and achievement of the National Foundation augur well for the future. The record of the past gives confidence that the same approaches that brought victory over one group of crippling diseases will bring similar victory in other fields as well."[35] A cartoon in the *Philadelphia Daily News* depicted a muscular blond male March of Dimes boxer defeating polio in a fighting ring with boxing gloves labeled "Salk vaccine." The cartoon depicts medical science as the referee and shows other menacing chronic disease opponents lined up in the sidelines, waiting for their due (see fig. 1).

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[29] "Polio and Viruses, Plus Arthritis" *St. Louis Post* September 12, 1958, 2, Box 7, Folder: "Expanded Program, Publicity" MPR, MDA.

[30] George Voss, "Press Release," July 17, 1960, pg 3, Box 3, Folder: "Program material and press releases," MPR, MDA.

[31] "Approved Program," 20–21, 20 May 1958, Box 7, Folder: "Approved Program [booklet], May 20, 1958," Series 6, MPR, MDA.

[32] Ibid.

[33] "Probable Questions by Reporters and Suggested Answers by Mr. O'Connor at Press Conference, July 22, 1958," Box 7, Folder: "Televised Announcement," Series 6, MPR, MDA.

[34] War metaphors reflect a longstanding language of medicine as the act of battling disease, and the still-recent medical mobilization during wartime. There is a broader literature on how economic, mechanical, and gendered metaphors shape science and medicine difficult to summarize here, ranging from female bodies imagined as nurturing nests or productive machines or factories, to life as a "restless clock," and illness as an "excessive expenditure" sapping limited stores of energy (Martin 1988; Sontag 1990; Riskin 2016).

[35] "The National Foundation," *New York Times*, 27 July 1958, Box 7, Folder: "Publicity: News Articles, Editorials, Clippings" Series 6, MPR, MDA.

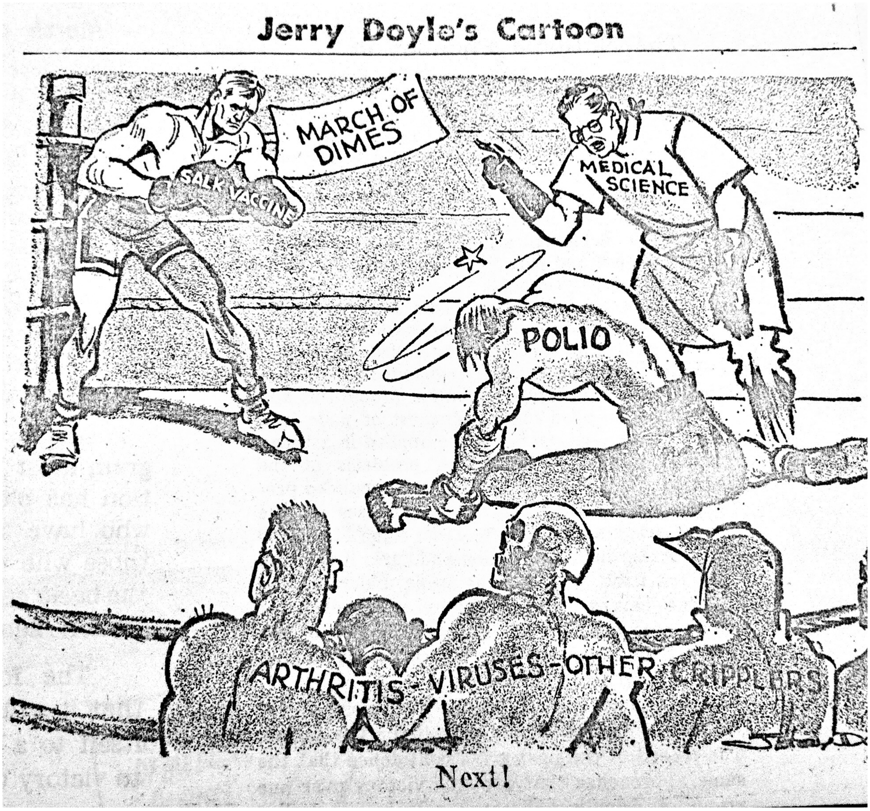

Figure 1. Cartoon on the National Foundation's Expanded Program in the *Philadelphia Daily News*, July 28, 1958.[36]

More critical perspectives emphasized lack of collaboration. One journalist pointed out that the March of Dimes had refused to join the United Fund, yet was essentially creating a large fund in the hands of a private charity with a similarly broad program.[37] Others noted the overlapping missions of various philanthropic organizations, suggesting rivalry over public fundraising with the Arthritis and Rheumatism Foundation and others.[38] One such article noted that the "voluntary non-profit health agency, has come of age … [or] at least to a stage of advanced adolescence. … [W]e now have a long, long list of foundations, associations, or societies all geared toward the conquest of some specific ailment and affliction."[39] These perspectives seem to be engaged in debates about local vs. national control of fundraising dollars and disease-targeted vs. broader charitable health and welfare efforts.

The Expanded Program combined a desire to reduce the shame associated with congenital malformations, deemphasizing familial taint, with efforts to use medical research science to

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[36] Jerry Doyle's Cartoon, Philadelphia Daily News, 28 July 1958, Box 7, Folder: "Publicity: News Articles, Editorials, Clippings," Series 6, MPR, MDA.

[37] Local charitable efforts, called United Funds or Community Chests, later became consolidated as the United Way, Inc. (Aft and Aft 2004).

[38] George P. Voss and Dorothy Ducas to State Representatives, "Memorandum" 8 August 1958, Box 7, Folder: "Publicity: News Articles, Editorials, Clippings," Series 6, MPR, MDA. Also, "Victory Through Dimes" *Washington Post* July 27, 1958 in same folder.

[39] "Editorials: The National Foundation," *New York Medicine*, 20 August 1958, 587– 589. (Circulated to NF staff by Raymond Barrows, September 8, 1958.) Box 7, Folder: "Publicity: news articles, editorials, clippings; 1958," Series 6, MPR, MDA.

prevent or rehabilitate those born with unusual anatomy. The program was intended to be educational and destigmatizing, modifying community attitudes and shifting blame away from parents' hereditary problems: "A skilled and delicate interpretation would need to be done to overcome the prevalent belief that most birth defects are due to hereditary factors and therefore, by implication, to deficiencies in the parents."[40] Here, the NF endeavored to move away from the shaming of families with hereditary illness and the elitism associated with eugenics, even as they promoted high-quality births largely for upper and middle-class White families. The program also raised questions about how to convey information about diverse, sometimes intractable and highly stigmatized, childhood impairments in a way that would maintain public interest and fundraising efforts.

Changing approaches to prevention of infant anomalies

The new program combined a broad program of scientific research with financial aid for the treatment and rehabilitation of specific paralytic disorders for those under the age of 18. However, the allocation of funds between these aims remained difficult. Based on internal memos about medical aid criteria and the poster children chosen in the first few years of the expanded program, neural tube defects were a major focus, particularly spina bifida. In 1959 the NF chose three children, one for each area of focus (polio, congenital malformation, and juvenile arthritis). One of them, Jeffrey Reil, was "born with an open spine." The poster children of 1960 and 1961, toddlers Mary Beth Pyron and Linda Gail Breese, were also born with spina bifida (Breese also had hydrocephalus).

As with polio poster children, the public faces of affected children were sanitized emblems of vulnerability (Altenbaugh 2015, 70–73). The NF poster children for 1959–1961 were appealing and well dressed, with few signs of impairment save for devices (like crutches or braces) intended to facilitate their mobility. As disability historian Paul Longmore demonstrated, images of impaired children were a common part of the iconography of charitable campaigns in the late nineteenth and twentieth centuries, such as the Warm Springs Foundation or the Easter Seal Society, which sponsored contests to select children for their campaigns (Longmore 2013). Although common aspects of human experience, pain and suffering are difficult to depict visually, and Rosemarie Garland-Thomson has argued that photographs of physically disabled poster children served as representations of suffering to evoke sympathy and empower the agency of the viewer. By the 1950s, such images were deployed not only to depict suffering, but also to mobilize people to contribute with the aim of curing, promising "restoration to normalcy" (Garland-Thomson 2001, 355–356).

It almost does not bear mention that little publicity was directed at the experiences, needs, or lives of disabled adults. One newspaper article cited NF Medical Director Thomas Rivers, who warned about prenatal risk factors like rubella, narcotics, X-Rays or anesthesia and stated that "through rehabilitation, many malformed babies can be helped to become useful and productive adults" (McCormack 1959, 15). Productivity and usefulness were seen as essential to valuable adult lives. Much as polio survivors were rendered invisible by a successful vaccine, little provision was made for grown children, particularly those who fell short of these goals.

Despite a broad scientific research program, in the late 1950s and early 1960s NF publicity and medical aid focused on children with neural tube disorders. After the mission changed, NF initially continued medical support for polio patients, but added financial aid that targeted infants, children, and adolescents through eighteen years of age with "progressive hydrocephalus, encephalocele or symptomatic spina bifida."[41] In 1958, the NF circulated medical information on

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[40] Ibid., 17.

[41] "Expanded Program of the National Foundation," 8, Box 7, Folder: "Development and Planning, 1952-1959," Series 6, MPR, MDA.

meningocele, meningomyelocele, and hydrocephalus among their staff (these are defined by fluid in the brain and two different types of exposed spinal material, one associated with damaged meninges and the other with protruding portions of the spinal cord and impaired function of the lower body).[42]

Though its publicity focused on images and stories about children with spina bifida, the NF research program was far broader, supporting a number of scientific efforts to study, diagnose, or prevent developmental disability. A press release from 1960 summarizes their key activities to address (as their header then read) *crippling* arthritis, *crippling* birth defects and *crippling* polio.[43] In the two years since changing their program, the NF continued work in polio research, rehabilitation and vaccine education, allocating 2.2 million to establish six arthritis and birth defect study centers. Two NF clinical research centers, at Ohio State and Vanderbilt universities, were focused on "major birth defects (notably open spine, open skull and excess water on the brain)." The other centers focused on arthritis and rheumatism. In addition to this clinical work, twenty-two laboratory studies were funded to study the "enigma of birth defects." Funded topics included viral infection in pregnant women and the hereditary basis of birth defects, including identification of a chromosomal abnormality associated with the connective tissue disorder, Marfan syndrome.

Grants detailed in June 1961 further elucidate the NF's wide-ranging interests.[44] They gave grants for research on infant vertebrae, spinal cords, and other studies of the central nervous system, as well as on bile defects. Other grants were for clinical studies to improve care for children with congenital defects, and for chromosomal research on unusual sexual differentiation. The NF funded research on causes of cleft palate, congenital skeletal disorders and metabolic bone diseases, on genes for galactosemia, on birth defect genetics, on abnormal metabolism of phenylalanine (to Robert Guthrie, who invented a biochemical test for PKU), on chemical and nutritional deficiencies, drug treatment for hydrocephalus, and on the effects of steroid hormones on sexual differentiation.

In practice, the diversity of conditions gave weight to studies that classified and diagnosed anomalies, part of the burgeoning field of medical genetics. In the early 1960s, NF research grants encompassed the medical diagnosis of congenital defects, and the basic sciences of genetics, development, and perinatology rather than, for example, needs assessments of disability or orthopedic studies. Their research program prioritized laboratory and clinical work over epidemiological studies (considered the purview of government). In essence, they trusted that funds for better scientific understanding of congenital disability (more scientific or technical knowledge) would more efficiently lead to prevention or treatment options than other applied research arenas such as patient needs assessments, orthopedics, or rehabilitation.

Meanwhile, the 1958 commitment to continued medical support for polio patients was short-lived. By 1960, the NF stopped funding long-term medical care for polio survivors and required county chapters to send twenty-five percent of their campaign funds to the central Medical Scientific Research Fund (compared to 7–11 percent the NFIP spent on polio research 1938–1958) (Baghdady and Maddock 2008). In August 1962, as the public responded to news about thalidomide-associated birth defects, the NF provided publicity materials to local chapters and daily newspapers about twenty-three special treatment centers for birth defects "to promote, develop, improve or expand differential diagnosis services" and provide care and consultation services.[45]

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[42] "Medical information, 1958" 4, Box 7, Folder of same name, Series 6, MPR, MDA.

[43] George Voss, "Press Release," July 17, 1960 Box 3, Folder: "Program material and press releases," MPR, MDA.

[44] Science Information, Public Relations Department, "National Foundation Research Grants in the Field of Birth Defects" June 30, 1961, Box 3, Folder: "Birth defects treatment centers, 1961–1973," MPR, MDA.

[45] Charles Massey and George P. Voss, "Memorandum," August 6, 1962, Box 3, Folder "Birth defects treatment centers, 1961–1973," MPR, MDA.

The NF's hopeful rhetoric combined advocacy for amelioration and prevention of developmental disability with fundraising for clinical and laboratory methods to diagnose and answer fundamental questions about the origins of congenital impairment. As Director, Apgar championed using science to improve neonatal outcomes. Apgar's speech to the Bergen County, NJ March of Dimes chapter in 1959 outlines the objective of preventing disability through medical research. She predicted, "Someday, when you read that 'the cause of cleft palate has been found', that 'club feet need not exist' or that 'protection against radiation has been found,' you will be thrilled, because you know you voluntarily chose to put your efforts and money into the March of Dimes."[46] NF rhetoric combined a plea for dispersed fundraising with explicit promises (some might say, unrealistic promises) that scientific research would provide a return on the investment by vanquishing common types of infant disability. In the case of some diseases and conditions, such as rubella-associated disabilities, congenital anatomical defects correctible with surgery, and erythroblastosis due to maternal-fetal Rh incompatibility, medical or technological fixes had dramatic results. In the 1950s, it seemed that improved nutrition, vaccines, and prenatal therapies might vanquish congenital malformations, much as improved diets and vitamins had largely eliminated childhood nutritional deficiencies such as rickets and antibiotics combined with vaccines had reduced childhood mortality from infectious disease (Apgar 1968).[47]

The NF's language implied that the morally correct course was to pursue basic research into the underlying the causes of birth defects in order to eliminate them, and only rarely raised questions how to define and delineate what constitutes preventable neonatal disability. Apgar wrote in 1962 that it was "time to sweep away the fatalism and indifference," as it was *immoral* not to use newly acquired knowledge to have healthier children (Apgar 1962, 20–2). Voicing a common opinion of the era, she sometimes implied that another morally correct course was for families with inherited illnesses to better control their reproduction (McCarty 1963).[48] Nevertheless, anatomical or functional disorders diagnosed at or shortly after birth proved a resistant target for elimination. Indeed, characterizing anatomical disabilities that children were born with as something that needed to be prevented gradually became more contentious as, by the late 1960s, abortion became one (still rare) means of preventing birth defects or genetic illnesses prenatally.

The March of Dimes helped fund clinics that diagnosed birth defects and provided services to parents with a family history or past experience with birth defects. They tried to maintain neutrality about amniocentesis and abortion, yet their approach tended to conceptualize fetuses as patients and unborn children even as they also funded genetic counseling and prenatal diagnostic clinics that, at least in some locations, began to offer the option of identifying and terminating affected pregnancies. When editorials in the late 1960s questioned the use of amniocentesis and abortion to terminate pregnancies affected by birth defects, Virginia Apgar tended to portray the NF's position as neutral, simply responding to a controversial societal issue.

For instance, the journalist James Conniff (father of a child with Down syndrome) wrote a *New York Times* article about fetology, "The World of the Unborn," which raised questions about the appropriate uses of amniocentesis (Conniff 1967). One physician quoted drew parallels between the elimination of defects and the Holocaust, saying: "Jews especially . . . ought to recognize that in recommending the elimination of one kind of 'defect' . . . they are ironically echoing the satanic

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[46] Apgar, "Speech given to Bergen County March of Dimes," 1959, Box 11, Folder 2, Series 2: Correspondence, 1925–1974, Virginia Apgar Papers (VAP), Mount Holyoke.

[47] See Virginia Apgar's summary of the field in "Congenital Anomalies, 1968," Box 11, Folder 11, VAP. This speech at the 1968 International Anesthesia Research Society meeting highlights genetics, rh, and rubella as areas of progress preventing congenital anomalies. Apgar also notes thalidomide and progestins as teratogenic drugs and acknowledges the expanding definition of birth defects to include functional deficits diagnosed in early infancy.

[48] For instance: "One woman with a family history of congenital heart malformations, who had produced three children with heart defects among her four, wanted to know the odds concerning the fifth she was carrying. 'I felt that she should have asked someone this question a good while earlier,' Dr. Apgar said" (McCarty 1963, 2).

philosophy which sought to eliminate another kind of 'defect' at Auchwitz [sic], Dachau, Belsen, and so on" (Conniff 1967, 96–97). References to the Holocaust have emotional valiance, and this quote alarmed several readers, who wrote to point out that there were major issues of scale—how could he compare the murder of more than six million with one terminated, possibly nonviable, pregnancy? Another described herself as a parent of a children living with Down syndrome, who naturally loved her child, but said she definitively supported efforts to prevent the birth of infants with Down syndrome prenatally (Morris 1967, 12). In letter responding to Conniff's article, Apgar acknowledged that the March of Dimes' approach did not preclude the termination of malformed fetuses, and restated the Foundation's tagline "every child has a right to be well born." She stated, "The March of Dimes position is simply that new advances in science and medicine are posing difficult moral and philosophical questions. We do not propose to supply the answers to the questions since they obviously can only be answered by public consensus" (Apgar 1967). Public consensus about abortion, the meaning of eugenics, when it was justifiable to attempt to prevent infant anomalies, and how to uphold human flourishing and care for the severely disabled, would remain elusive. Advocacy for reproductive autonomy linked to the women's health movement, combined with fears about birth defects, helped propel further decriminalization of abortion—which began with legislative heterogeneity across states but expanded nationally after the 1973 *Roe vs. Wade* decision (Reagan 1997). Sex or disability-selective abortions, used by some families with inherited hemophilia since the mid-1950s, became more routine once amniocentesis could detect chromosomal aneuploidies, particularly following a series of successful wrongful birth lawsuits in 1978–1979 (Fuchs and Riis 1956, 95–100; Casper 1998; Cowan 1994, 2008; Nicolson and Fleming 2013; Löwy 2017).

Presumably, the NF's language of eliminating birth defects and funding clinical diagnostic centers for birth defects became less palatable to some constituencies as a result of the conflict over the further legalization of abortion and women's advocacy for greater reproductive autonomy. Certainly, eliminating fetuses thought likely to be born with birth defects posed different challenges than eliminating an infectious disease such as polio. Voices that advocated for collective approaches to the prenatal prevention of birth defects, for the wellbeing of children and to reduce the burden on families and society (a utilitarian argument), gradually gave way to the narrative of giving individual parents reproductive autonomy and choices through diagnostic technologies (a deontological argument, hinging on parents' reproductive rights and self-determination). At the NF, a memorandum on amniocentesis was circulated internally in 1972, stating that the "decision to terminate is a parental decision, not under March of Dimes purview."[49] In their 1972 annual report, contemporaneous with debates about further legalization of medical abortion, the NF moved away from the language of eliminating birth defects and used more moderate language focusing on the value of perinatology to improving maternal and infant health.[50]

Responding to thalidomide: Public fears and professional deliberations

Some of the reportage around birth defects is likely linked to fears and reportage on the sedative thalidomide, which initially seemed safe and less likely to cause overdoses than alternatives (Daemmrich 2002). Rubella epidemics in the mid-1960s likewise drew attention to preventable birth defects, opening up public conversations about dangers to pregnancy, disability, and abortion (Reagan 2010). Morton Mintz broke the story about thalidomide to a broader American public in a July 1962 *Washington Post* article that lauded the FDA for keeping the drug off the U.S. market (Mintz 1962). Shortly after, a *Life* article, "The Drug that Left a Trail of

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[49] George Voss, "Memorandum," March 14, 1972, Box 3, Folder: "Amniocentesis," MPR, MDA.

[50] Harry Green, "The National Foundation/March of Dimes Annual Report, 1972," Box 1, Folder: "Annual Reports, 1939-1994", MPR, MDA.

Heartbreak," showed images of a dimpled British baby in white dress with bare feet and no arms juxtaposed in a two-page spread with an image of a troubled expectant mother (1962).

Virginia Apgar had first heard of birth defects attributed to a popular tranquilizer called Contergan in February 1962, as her colleague the pediatric cardiologist Helen Taussig made a trip to Germany to consult on heart-related complications. By then, media in Germany had publicized alerts about the drug, but American audiences were still largely unaware. Taussig reported on her trip in April 1962 to colleagues in Baltimore, estimating that between 3,000 and 5,000 children in West Germany and England were affected by 1962, and that in addition to *phocomelia*, or shortened limbs, children had been born with ear malformations, hemangioma of the forehead and face, malrotation of the gut, rectal and anal atresia, and cardiac anomalies. Reassuringly, the use of the drug before pregnancy had not caused disability (indicating no genetic effects).[51] Thalidomide affected thousands of children in at least forty-six countries, but because of delayed drug licensing for sale in the U.S. it reportedly affected less than twenty Americans—despite rather vague testing at the time, with investigational drugs often being simply handled out as samples (Kelsey 1988).

Following such revelations, many feared that pregnant women were consuming a plethora of deleterious drugs, whose fetal effects would go undetected absent dramatic anatomical differences as with thalidomide. By August 6, 1962, in response to widespread publicity about thalidomide (Carpenter 2010; Bale 1992), the NF began to "plan for a broad public education program to discourage the use of drugs during pregnancy."[52] Furthermore, they planned a consultant's meeting of "six invited guests" and seven NF staff members in September 1962. Participants decided, after much discussion, to initiate a "public education program for women of reproductive age and even adolescents, aimed at better health for better babies."[53] As part of this program, "premarital, pre-pregnancy examinations, care with radiation and drug ingestion, and change of habits for the better should be urged. Smoking was high on the list of undesirable habits." However, "It was noted that there was no scientific proof in human beings for any of the above advice."[54] All the physicians were pessimistic about teaching medical students "pharmaceutical nihilism." Attendee Dr. Pfeiffer thought that common drugs such as aspirin and nasal sprays might be related to birth defects. Another attendee, Dr. Noyes, emphasized that the "responsibilities of pregnancy, not its privileges alone, should be stressed" in the NF program.[55] This range of opinions illustrates that medical professionals and NF staff felt the need to publicize the risks of recreational drugs or pharmaceuticals and encourage medical surveillance and healthful living during pregnancy to prevent birth defects, even as they acknowledged at the time there was insufficient scientific evidence to support this position, or to define precisely what advice and guidance to offer.

In the 1960s and early 1970s, researchers set out to illustrate the deleterious fetal effects of maternal behaviors such as smoking, drinking, or consuming drugs during pregnancy (Kandall 1996; Oaks 2001; Golden 2005).[56] The NF's framing of the problem immediately post-thalidomide typically highlighted the profligate use of pharmaceuticals, recreational drugs, and cigarettes by individual pregnant women, rather than the diversity of human developmental outcomes, larger

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[51] Apgar, "Professional Diary 1962," 34, Box 2, Folder 4, VAP.

[52] Doctors Clarke, Boyd, Markham, Voss, and Schuman met to discuss the thalidomide story. Virginia Apgar, "Professional Diary 1962," 66, Box 2, Folder 4, VAP.

[53] The consultant's meeting occurred at Hotel Pierre in New York City on September 20, 1962, and was attended by Dr. Lowry, Dr. Mudge, Dr. Pfeiffer, Dr. Barnes, Dr. Noyes, and Dr. Robertson in addition to NF staff members: Dr. Boyd, Dr. Bergsma, Mr. Charles Bennett, Mrs. Ethel Brown, Mrs. Virginia Allison and Dr. Apgar. Virginia Apgar, "Professional Diary 1962" 75–76, Box 2, Folder 4, VAP.

[54] Ibid.

[55] Ibid.

[56] A number of historians and social scientists have shown how public health campaigns often criminalized or targeted behaviors of pregnant women, particularly women of color.

socio-structural concerns about health inequities, physicians' prescribing practices, or the effects of waste disposal in industrial societies. The model they promoted thus tended to oversimplify the complex, multifactorial, and diverse processes of unusual fetal growth, characterizing it as caused by the misguided habits of individual women who were insufficiently compliant with medical supervision.

Drugs were an area of particular concern in the late 1960s, amidst tumultuous civil rights, countercultural, and anti-war movements. For instance, a 1968 press release with an image of a child affected by thalidomide was titled "Household Drugs May Cause Defects, March of Dimes Physician Warns." Apgar is quoted, "The word 'drugs' has come to mean only the addicting narcotics and barbiturates, or the mind-altering marijuana, LSD, and 'speed.' But the truth is that drugs include the whole range of chemicals human beings may take in the form of pills, powders, capsules, injections, inhalants or by absorption through the skin."[57] Though this quote highlighted effect of chemicals passing into maternal bodies, the emphasis was not exclusively directed at women and development. Around the same time, the March of Dimes also published an advertisement in *Life Magazine* on the dangers of chromosomal breakages linked to LSD. The piece featured an image of a young man and woman, and the headline read, "Give me one good reason why I shouldn't use LSD! We can give you 46."[58] Public health messaging about drugs and individual responsibility to avoid birth defects occurred in tandem with high income inequality, stigmatizing discourses about mothers of color, and fierce opposition from medical organizations like the American Medical Association to extending health care to all citizens (Briggs 2017; Starr 1982). It would take the environmental and reproductive justice movements of the 1990s to affirm that people should not only have the right to avoid unwanted pregnancy or prevent infant disability, but should also be enabled to have and raise children, if they wished, in safe and healthy environments (Ross and Solinger 2017).

Advice on birth defect prevention: Entangled goals of research fundraising and health education

Shortly after changing their mission, the NF circulated educational and press materials, such as an information leaflet for pregnant women printed from January 1961, called "Facts about Birth Defects: Do's and Don'ts for Expectant Mothers" (see fig. 2).[59] This document highlighted the following categories: consultation with a medical professional prior to pregnancy, x-rays, diet, diseases, powerful drugs, and incompatible blood types.

In the post-thalidomide publicity campaign, the NF also produced promotional materials aimed at volunteers and the press. Apgar and other NF staff prepared press releases and "Swiss cheese stories"—essentially, birth defect publicity Mad Libs—that were sent to chapters of the March of Dimes to be filled in with local details.[61] In addition to reviewing research grants and communicating with scientists, Apgar wrote about the prenatal risks of birth defects for popular magazines such as *Good Housekeeping* and the *Ladies' Home Journal* and published an advice manual in 1972, titled, *Is My Baby All Right?* (Apgar 1962, 20–22; 1966b, 35; 1966a, 46; Apgar and Beck 1972). Her diary entries are peppered with interviews and persistent energetic engagement

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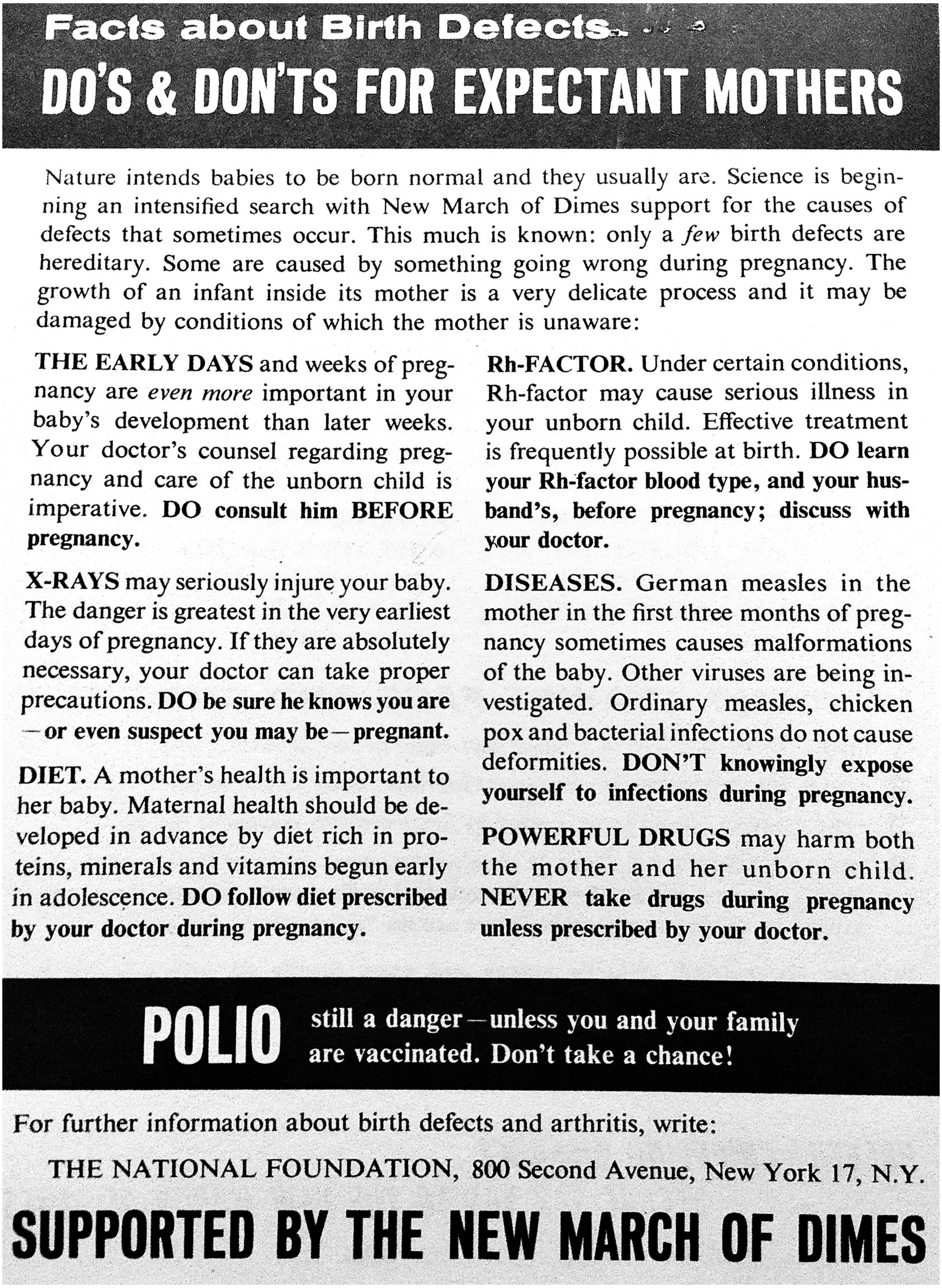
[57] NF Public Relations Department, "Household Drugs May Cause Defects, March of Dimes Physician Warns" December 9, 1968. Folder: "Genetics," Series 3, "Birth Defects," MPR, MDA.

[58] "Give Me One Reason Why I Shouldn't use LSD" circa March 1969, Folder: "Genetics," Series 3, "Birth Defects," MPR, MDA.

[59] Anonymous, "Facts About Birth Defects: Do's and Don'ts for Expectant Mothers" January 1961, Box 3, Folder: "Brochures and Warnings, 1959," MPR, MDA.

[60] "Facts about Birth Defects: Do's and Don'ts for Expectant Mothers" Folder: "Brochures & Warnings, 1959" Box 3, Series 2, MPR, MDA.

[61] For examples, see Box 3, folder "Birth Defects Education Program, 1966," MPR, MDA.



Facts about Birth Defects

DO'S & DON'TS FOR EXPECTANT MOTHERS

Nature intends babies to be born normal and they usually are. Science is beginning an intensified search with New March of Dimes support for the causes of defects that sometimes occur. This much is known: only a *few* birth defects are hereditary. Some are caused by something going wrong during pregnancy. The growth of an infant inside its mother is a very delicate process and it may be damaged by conditions of which the mother is unaware:

THE EARLY DAYS and weeks of pregnancy are *even more* important in your baby's development than later weeks. Your doctor's counsel regarding pregnancy and care of the unborn child is imperative. **DO consult him BEFORE pregnancy.**

X-RAYS may seriously injure your baby. The danger is greatest in the very earliest days of pregnancy. If they are absolutely necessary, your doctor can take proper precautions. **DO be sure he knows you are—or even suspect you may be—pregnant.**

DIET. A mother's health is important to her baby. Maternal health should be developed in advance by diet rich in proteins, minerals and vitamins begun early in adolescence. **DO follow diet prescribed by your doctor during pregnancy.**

Rh-FACTOR. Under certain conditions, Rh-factor may cause serious illness in your unborn child. Effective treatment is frequently possible at birth. **DO learn your Rh-factor blood type, and your husband's, before pregnancy; discuss with your doctor.**

DISEASES. German measles in the mother in the first three months of pregnancy sometimes causes malformations of the baby. Other viruses are being investigated. Ordinary measles, chicken pox and bacterial infections do not cause deformities. **DON'T knowingly expose yourself to infections during pregnancy.**

POWERFUL DRUGS may harm both the mother and her unborn child. **NEVER take drugs during pregnancy unless prescribed by your doctor.**

POLIO still a danger—unless you and your family are vaccinated. Don't take a chance!

For further information about birth defects and arthritis, write:

THE NATIONAL FOUNDATION, 800 Second Avenue, New York 17, N.Y.

SUPPORTED BY THE NEW MARCH OF DIMES

Figure 2. "Do's and Don'ts for Expectant Mothers:" Pamphlet Warning Potentially Pregnant Women about Prenatal Risks, c1961[60]

with journalists, including reviewing their articles.[62] Articles covered the following points: 1) the problem of birth defects was greater than previously imagined; 2) many parents worried about having abnormal children; 3) previous ideas of maternal impressions or "tainted blood" were wrongheaded and science showed preventable causes of birth defects; 4) medical science was working towards preventing birth defects in the future, with some successes; and 5) in the meantime, there were actions that expectant mothers could take to ensure a healthy baby, among them avoiding all drugs, x-rays, infections, and excessive drinking and smoking.

For example, in the article "Medicine's Next Frontier," in *PTA Magazine,* Apgar argued that, "the number of defective children is far greater than many of us realize," and that the NF's mission was to overcome fatalism and address the "enormous problem of congenital defects" in order to produce "better, healthier children" (Apgar 1962, 20–21). In "New Ways to Save Your Unborn Child," in the *Ladies' Home Journal*, Apgar wrote that though 93 percent of babies were born healthy and normal, seven percent were not and mothers needed to know a great deal more about how to prevent birth defects. She argued that responsibility began at marriage: "When do you begin taking care of your baby? As soon as you're married." Such phrases expansively defined even non-pregnant women as at risk—and fetuses or embryos as babies—while conservatively expecting only married women to become pregnant.

Furthermore, drugs of all types were untrustworthy. An article published in May 1963 in the *Omaha World Herald* trumpeted: "Expert Suspects Even Aspirin in Pregnancy."[63] Many followed, warning about drugs as particular dangers to pregnancy:

> Even though testing with animals is inconclusive, doctors who treat pregnant women are more and more suspicious of everything in the medicine chest. They have found that some of the most common medicines can produce defects in animals—aspirin, antihistamines, anti-nausea drugs, laxatives, nasal decongestants, even caffeine. . . . I believe that most women would endure a stuffy nose, a headache, or even a little nausea, rather than take a chance." (Apgar 1966a, 46)

Apgar's published advice was sometimes ambivalent about medical supervision, as it emphasized faith in the advice and prescriptions written by physicians, while at the same time recommending that pregnant women not treat their own illnesses and "avoid taking anything that is not food."[64] The thalidomide tragedy pointed to the perils of having complete faith in the safety of physicians' prescriptions, highlighted that fetal effects were often most severe in the first trimester before the pregnancy was apparent, and demonstrated that the evidence to support (or reject) behavioral reform for pregnant women was limited. Nevertheless, Apgar's advocacy in the popular press sometimes portrayed maternal vigilance as sufficient to avoid infant impairment.

Here the dissemination of narratives about a public health crisis of infantile disability and scientific breakthroughs in prenatal prevention were harnessed to prescriptive advice for the potentially pregnant. Public health messaging that assumed infant bodily differences were both common and necessarily undesirable was linked to fundraising for scientific research and parents' hope for a bright future for their children. Women were told to dismiss treating their own health needs pending the possibility of pregnancy and assume responsibility for ensuring fit citizens even as they lived in polluted and stratified societies largely beyond their control.

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[62] Apgar, "Professional Diary," 6-10, 1961, Box 2, Folder 3, VAP.

[63] "Expert Suspects Even Aspirin in Pregnancy," *Omaha World Herald*, May 23, 1963. Clipping in Box 5, Folder 8, Series 2, VAP.

[64] Virginia Apgar, "Be Good to Your Baby Before it is Born," *Baby Post*, November 1963, 5, 17, Box 1, Folder: "Baby Post, 1963," MDA.

Conclusion

This article traced the rise of birth defect prevention advocacy, emphasizing how the growth of specialized expertise in concert with NF research funding and publicity popularized the term "birth defect" and publicized a particular modernist medico-scientific vision of preventing infant disability. The NF's public information campaigns combined marketing, health education, and fundraising efforts that simplified the complexity of infant disability. They initially made assumptions about what kinds of disabilities were worthy or capable of rehabilitation (prioritizing central nervous system anomalies that caused mobility handicaps in children) based on their experience with the paralyzing effects of polio. NF staff demonstrated ambivalence about the use of prenatal diagnosis and pregnancy termination as a means of birth defect prevention (eliminating fetuses thought likely to be born with disabilities). The NF shifted their rhetoric about eliminating birth defects in response, emphasizing individual parental choice and maternal and child health and moving away from language that urged elimination of birth defects or highlighted collective or social benefits of birth defect prevention.

Elite specialists and philanthropists helped shape judgements about who should and should not inhabit the world (Hubbard 2006). They contributed to popular advice literature, much of it written by Virginia Apgar or the NF publicity department, which portrayed birth defects as a large public health crisis and emphasized diverse prenatal risks that all (married) women must avoid in order to prevent infant anomalies. Often written by and for women, this literature disseminated perspectives from burgeoning medical genetics and teratology research, which had aided the gradual transformation from congenital malformations as "unavoidable accidents of nature" to "birth defects" with specific environmental or genetic causes.

Alison Kafer has shown how disabled bodies are linked to "grim imagined futures" (Kafer 2013, 2). Fetuses and embryos have often been invested with historically specific anxieties about motherhood, personhood, and national identity, serving as icons of human life and emblems of future vulnerability (Dubow 2011; Morgan 2009; Dunaway 2015). Advocacy about prenatal prevention leveraged parents' hope and aspirations for their children's future wellbeing towards fundraising for medical research innovation and technologically mediated gatekeeping of specific bodily and functional differences. In 1962, cases of shortened limbs, heart defects, and other neonatal disabilities linked to thalidomide widely publicized in Germany and worldwide created a tidal wave of public concern about birth defects. Expectant mothers, pregnant or otherwise, were admonished to monitor their behavior in an effort to mitigate prenatal risks, while they waited for the future rewards of scientific progress.

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Heather Dron is a historian of science, medicine, and public health who studies pregnancy and childhood disability. She completed her PhD in history of health science at the University of California San Francisco and is a former fellow at the Sterilization and Social Justice Lab and the Stanford Center for Biomedical Ethics. Her dissertation examined research on environmental exposures during pregnancy in the mid-twentieth century U.S. This work raised epistemic and health communication questions. Researchers used diverse methodologies to study teratogenic or mutagenic health effects, linked them to pregnancy outcomes such as infant anomalies ("birth defects"), and worried about how to communicate findings to potentially pregnant women. Subsequent work examines the history and ethical implications of eugenics and genetics in California. Dr. Dron uses mixed methods to study patient experience and consent for involuntary sterilization and other reproductive health interventions. As such, her work engages with a wide-ranging scholarship pertaining to eugenics, medical genetics, reproduction, and disability.

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