

6 After the End of Polio

In 1963, Katalin Parádi meticulously arranged the patient files of polio patients. The girl who had emerged from a bomb shelter in 1956 to get to her physical therapy session and who had been sleeping on a makeshift bed in the early days of the Heine-Medin Hospital now had an important task to complete as polio epidemics drew to a close in Hungary. Having stayed in the hospital as an administrator, for weeks she took copies of each of the patient records, tracked down the address of every patient and sent the copies to their local health centre in the hope that at the other end a similarly meticulous administrative procedure would ensure the continued medical care of polio patients.¹ The Heine-Medin Hospital, as such, was closing down and being transformed into a general children's hospital. Polio was officially over and done with.

From as early as 1960, parents no longer needed to look for the reports on outbreaks on the back page of the newspaper, and children could freely seek relief from hot summer days in public pools and baths. In this 'second world' country with an economy of shortage, polio was, in technical terms, eradicated: not through an international programme, humanitarian aid or pressure from a superpower, but instead as something intrinsic to the country's self-identified socialist health system. The epidemic of 1959 proved to be the last in the country's history, and by the early 1960s, polio had all but disappeared from the epidemic reality of Hungary. As soon as 1962, journal articles were discussing in a matter-of-fact manner the fact that polio was no longer present in the country.² Between 1961 and 1990 a total of 66 new cases of polio were recorded in Hungary. Out of these cases, 56 were vaccine-derived paralytic polio (VAPP), one was an imported case and in four cases virological studies were not able to confirm the clinical diagnosis. This left five wild, domestic polio cases in the course of twenty-nine years, of which four were a cluster

¹ Parádi, interview by Vargha, 27 January 2010.

² Andor Bándi, 'A Folyamatos Oltásról', *Népegészségügy* 43, no. 5 (1962): 150–52, at 150.

outbreak in an isolated rural community in 1966 and the fifth, last case was recorded in 1969.³

Our story could end here as well, a dreaded epidemic going out with a bang. However, there is still much to tell about the era after the end of polio. The history of the disease in Hungary invites us to look further and reconsider the conventional take on the ways in which epidemics work. What happened to polio as a disease once it was over? What were the consequences of proclaiming the end of the disease on a global and local level? Where and for whom did polio end and who was excluded or forgotten?

What comes after the end of a disease is more often than not relegated to epilogues and usually comes up as an afterthought to the master narrative. Yet diseases are often imprinted on the bodies of survivors, societies and cultures. Epidemics may change economic structures and social interaction, and shape practices of international intervention and attitudes towards healthcare. In some cases, the proclaimed end of a disease leaves individuals or whole societies and states without resources previously guaranteed by the perceived epidemic threat. In others, the action of looking back after the end creates space for moral judgements on individuals, societies, governments and international organisations.

The course that the epidemic narrative runs is usually well-defined. Charles Rosenberg, in his classic paper, 'What is an epidemic?', stresses the episodic nature of epidemics and lays out the particular dramaturgy of the way epidemics take place. 'Epidemics start at a moment in time, proceed on a stage limited in space and duration, follow a plot line of increasing and revelatory tension, move to a crisis of individual and collective character, then drift toward closure.'⁴ This narrative has been little contested since. Priscilla Wald, in a more recent work, *Contagious*, portrays a similar plotline for what she calls the outbreak narrative, which 'in its scientific, journalistic and fictional incarnations . . . follows a formulaic plot that begins with the identification of an emerging infection, includes discussion of the global networks throughout which it travels, and chronicles the epidemiological work that ends with its containment.'⁵ While Wald's book takes important steps towards critically assessing the narrative by focusing on its consequences, stakes and cultural, scientific and political significance, the questions of how and when these narratives end are little raised. The end of the storyline in the case of epidemics and outbreaks, then, is successful containment. As such, the story of this book

³ Elza Baranyai, 'Oltási Poliomyeitis', in *A Gyermekbénulás Elleni Küzdelem*, ed. Rezső Hargitai and Ákosné Kiss (Budapest: Literatura Medica, 1994), 162–68.

⁴ Charles Rosenberg, 'What Is an Epidemic? AIDS in Historical Perspective', *Daedalus* 118, no. 2 (1989): 1–17.

⁵ Priscilla Wald, *Contagious: Cultures, Carriers, and the Outbreak Narrative* (Durham, NC and London: Duke University Press, 2008), 2.

would end here, with dwindling numbers of polio cases and the disappearance of the disease.

Disability historians have been at the vanguard of moving past this narrative. As Catherine Kudlick pointed out in a recent paper on the survivors of smallpox, epidemics have a hidden history interwoven with disability and survival. Because of this, disability history has the potential to transform the way we understand the impact of epidemic disease, not just at the level of individual reactions but also at the level of social and political responses. By paying attention to survivors rather than mortality, Kudlick argues, we can re-imagine epidemic scripts.⁶ Along these lines, disability historians Daniel Wilson and Julie Silver's research on post-polio syndrome, oral history projects such as Polio's Legacy and memoirs point to the lingering presence of polio's imprint on bodies and societies and the resurfacing of a disease that ended long ago.⁷

Global health history can benefit noticeably from these perspectives and take the opportunity to broaden the scope of its study. By placing the 'after' into the centre of analysis, we can gain a more nuanced understanding of what epidemics are, the way we might study them and who and what gets left out of the master narrative of beginning, crisis and end. This shift of focus also highlights the narrative's shortcomings and the stakes at hand as epidemic narratives shape global and local health policies.

The Hungarian case shows us how *after* the abrupt *end* of polio, the *ending* of the disease became synonymous with particular vaccine choices and epidemic management programmes. The successful application of the Sabin vaccine in both virological and organisational terms in Hungary then became part of standardised global public health models and policies across the Iron Curtain, informing global polio eradication programmes well into the twenty-first century.

Polio, of course, did not end in Hungary, or elsewhere in the world. For the thousands of children (and adults) who had already contracted the disease, the success of the Sabin vaccine did not bring an end to their polio. It did bring the end of the state's investment of resources in their care, as specialised polio services were dispersed. Nor did people stop getting polio. While the Sabin

⁶ Catherine Kudlick, 'Smallpox, Disability and Survival: Rewriting Paradigms from a New Epidemic Script', in *Disability Histories*, ed. Susan Burch and Michael Rembis (Urbana, Chicago and Springfield: University of Illinois Press, 2014), 185–200.

⁷ J. K. Silver and Daniel J. Wilson, *Polio Voices: An Oral History from the American Polio Epidemics and Worldwide Eradication Efforts*, The Praeger Series on Contemporary Health and Living (Westport, Conn.: Praeger, 2007); Gary Presley, *Seven Wheelchairs: A Life beyond Polio* (Iowa City: University of Iowa Press, 2008); Edmund J. Sass, George Gottfried, and Anthony Sorem, *Polio's Legacy: An Oral History* (Lanham, Md.: University Press of America, 1996).

vaccine was particularly apt at eliminating disease on a population-wide scale, its drawback was the sporadic appearance of vaccine-derived paralytic cases.

Some of these lingering effects of polio were integrated into the model of disease elimination, while others were mostly ignored. Hungary became particularly ideal for studying vaccine-derived polio and its effects on the population. The country, which was among the first to successfully control and eliminate polio, systematically used the same vaccination strategy and vaccine for over three decades and its internationally recognised experts published seminal works on the effects of vaccination that are still referenced in scientific publications today.

While vaccine-derived polio presented a problem for future vaccination strategies and the prospect of eradication, polio that had lingered, imprinted on the bodies of survivors, was often relegated to the realm of the past. As reminders of a bygone era of scientific uncertainties and failures in epidemic management, many people with polio found themselves pushed to the margins as funding for their care dwindled, practitioners specialising in polio care disappeared and polio was no longer a currency that could mobilise state and society. Furthermore, the unexpected survival of respiratory polio patients complicated the concept of the disease's end, as it blurred boundaries of human bodies, life, and medicine.

Polio as a disease changed drastically after epidemics ended. From an epistemic perspective, until the early 1960s, polio was a matter of virology and clinical medicine. The canon of both bodies of knowledge covered, explored and researched polio as a shared medical category. However, the clinical dimension was progressively eroded as the epidemic dimension of polio ceased to threaten the Hungarian and eventually broader populations. The knowledge of polio care was seldom discussed or further developed after the 1960s. International Poliomyelitis Conferences, with their rich discussions on both prevention and treatment, came to a stop in 1960. The European Association against Poliomyelitis integrated 'allied diseases' into its 8th Symposium programme in 1962 and meetings shifted from annual to sporadic, with the last one held in Bucharest on the epidemiology of polio in 1969.⁸

Discussions on post-polio syndrome altered this late twentieth- and early twenty-first-century perception of polio only slightly, and in limited ways. Post-polio syndrome as a term was coined in the early 1980s in the United States, as people who had contracted polio decades before began to experience

⁸ European Association against Poliomyelitis and Allied Diseases, ed. *L'épidémiologie de la Poliomyélite. 12e Symposium, Bucharest, 4-7 May, 1969: Rapport et Discussions* (Bucharest: Academiei Republicii Socialiste Romania, 1969); Porras, Báguena, and Ballester, 'Spain and the International Scientific Conferences on Polio.'

symptoms once again. Medical research and lay activity in post-polio syndrome increased through the 1980s and 1990s, and has been declining since, most probably because the affected population is not replenished, as is the case with other chronic diseases.⁹ North American experiences with post-polio syndrome point to the fact that polio as a complex disease with clinical manifestation has become a distant memory both on the individual and on the collective level. Through analyses of polio narratives, Amy Fairchild and Daniel Wilson have respectively argued that, for many, the onset of post-polio syndrome contested past experiences of conquering the disease, either through particular ideas of masculinity or through role models such as Franklin D. Roosevelt. The unexpected return of a disease experience and the frustrations it created has exposed the temporal situatedness of the meanings of polio.¹⁰

Despite the marked change in the meanings of the disease, polio as a global issue has remained strikingly stable since the 1950s. The particular political, social and scientific circumstances of the early Cold War that produced national and international public health programmes for preventing and treating polio may have changed over the decades, but the high priority given to the disease remained. In a way, this particular product of the Cold War outlived its own era and continues to shape global public health campaigns. Understanding these continuities and changes after the end of a disease is the focus of this chapter.

Global Significance: Eastern Europe's Role in Polio Eradication

The fact that Eastern European vaccination campaigns were successful was not lost on the international scientific community. Hungarian serological analyses and studies on vaccine-derived poliomyelitis in the decades following the end of polio in Hungary contributed to the understanding of the vaccine's risks and the refinement of its composition.¹¹ Moreover, successful mass vaccination campaigns with the Sabin vaccine, such as the Hungarian one, Cuba's campaigns in the 1960s and Brazil's in the 1970s came to serve as models for the current polio eradication programme.¹²

⁹ Lauro S. Halstead, 'A Brief History of Postpolio Syndrome in the United States', *Archives of Physical Medicine and Rehabilitation* 92, no. 8 (2011): 1344–49.

¹⁰ Fairchild, 'The Polio Narratives: Dialogues with FDR'; Wilson, *Living with Polio*.

¹¹ Paul E. M. Fine and Ilona A. M. Carneiro, 'Transmissibility and Persistence of Oral Polio Vaccine Viruses: Implications for the Global Poliomyelitis Eradication Initiative', *American Journal of Epidemiology* 150, no. 10 (1999): 1001–21; Victor M. Cáceres and Roland W. Sutter, 'Sabin Monovalent Oral Polio Vaccines: Review of Past Experiences and Their Potential Use after Polio Eradication', *Clinical Infectious Diseases* 33, no. 4 (2001): 531–41.

¹² Hull et al., 'Progress toward Global Polio Eradication'.

The beginnings of polio eradication are usually placed in the early 1980s following the success of the global eradication of smallpox in 1978.¹³ While some veterans of the smallpox campaign, like Donald A. Henderson, argued against the launch of new global eradication programmes (and suggested 'eradicat[ing] the word eradication' instead),¹⁴ the quest for the next disease to be globally eradicated began in 1980 at a conference held at the Fogarty International Centre, a research institute of the NIH near Washington D.C. Among the candidates were measles, schistosomiasis, yaws and poliomyelitis.¹⁵ Through interviews and conference proceedings, historian William Muraskin tracks the emergence of polio as the ultimate candidate for eradication and suggests that the scientific community far from wholeheartedly supported the decision. Rather, it was a small group of eradicationists who pushed the agenda of polio eradication through to become a global health policy.¹⁶ In 1988, the World Health Assembly passed a resolution to eradicate polio globally by the year 2000.¹⁷ As of the completion of this book, the Global Polio Eradication Initiative is still an ongoing programme.

An Eastern European perspective shows, however, that polio came up as a potential object of eradication much earlier in global health politics. Soviet researchers Chumakov and Vorosilova already regarded the Sabin vaccine as a potential tool for global eradication during the phase of vaccine development, and in 1960 polio eradication became an object of serious consideration at the WHO. The concept of polio eradication was already then very much connected to smallpox eradication, although less directly than later on in the 1980s. The beginnings of smallpox eradication were tied to experiences of disease control in a socialist regime: upon the return of the Soviet Union to the World Health Organisation, it was Viktor Zhdanov, Deputy Minister of Health, who proposed the global eradication programme. Zhdanov based his proposal on smallpox control in the Soviet Union, where compulsory vaccination introduced by the revolutionary government in 1919 led to the elimination of the disease by 1936. As historian Erez Manela points out, disease control was one issue that

¹³ William A. Muraskin, *Polio Eradication and its Discontents: An Historian's Journey through an International Public Health (Un)Civil War*, New Perspectives in South Asian History (New Delhi: Orient Blackswan, 2012); Nancy Stepan, *Eradication: Ridding the World of Diseases Forever?* (Ithaca, NY: Cornell University Press, 2011).

¹⁴ D. A. Henderson, 'The Global Eradication of Smallpox: Historical Perspectives and Future Prospects', in *The Global Eradication of Smallpox*, ed. Sanjoy Bhattacharya and Sharon Messenger, New Perspectives in South Asian History (New Delhi: Orient Black Swan, 2010), 35.

¹⁵ For the conference proceedings see Charles Stuart-Harris and Jr. DeWitt Stetten, 'Report on the International Conference on the Eradication of Infectious Diseases. Can Infectious Diseases Be Eradicated?', *Reviews of Infectious Diseases* 4, no. 5 (1982): 913–84.

¹⁶ Muraskin, *Polio Eradication and Its Discontents*.

¹⁷ The Forty-First World Health Assembly, 'WHA 41.28 Global Eradication of Poliomyelitis by the Year 2000' (Geneva: World Health Organization, 1988).

transcended the politics of avoiding international organisations from the early days of revolutionary Russia: the Soviet Union cooperated with the League of Nations in typhus control long before it actually joined the organisation.¹⁸

At the time of Zhdanov's proposal, eradication was all the rage in international public health. While efforts and ideas of eradication as absolute disease elimination can be traced back to the early twentieth century with yellow fever control,¹⁹ eradicationism²⁰ took off on a global scale in the post-war era. The Malaria Eradication Programme, framed by Cold War ideas of development and Western powers' struggle against political revolution, was launched in 1955 by the WHO.²¹

It was in this international political and scientific context that the potential for eradication became a central feature of the Sabin vaccine. The WHO's Expert Committee on Poliomyelitis addressed polio eradication in more detail in their Third Report in 1960, under a section titled 'The concept of polio eradication'. After reviewing both inactivated and live virus polio vaccines, the committee stated that the possibility of eradication had emerged with the appearance of the oral vaccine.

The widespread use of potent inactivated vaccine may well lead to a substantial reduction in the numbers of cases of paralytic poliomyelitis but can do little to eliminate the causal virus from the gastro-intestinal tract of man. The possibility of eliminating poliovirus as a human pathogen has been brought much nearer by the development and application of live poliovirus vaccine. If such a goal is envisaged, the first step will be to effect the mass vaccination of the whole population, or at least of those age groups most susceptible to infection, by administration of attenuated viruses within a short period of time. Following this 'blanketing' with vaccine viruses, special studies will have to be conducted to determine the most feasible means of maintaining the resistance of the population.

The report called on more studies to explore the differences in behaviour of the virus under various climates, in different socio-economic groups and healthcare systems of various resources. Rather than an immediate plan of action, the expert committee raised the very real possibility of eradication as an avenue to pursue for the future.

The report drew its conclusions on available national experiences 'on an extensive or massive scale [in] the USSR, Poland, Czechoslovakia, Hungary,

¹⁸ Erez Manela, 'A Pox on Your Narrative: Writing Disease Control into Cold War History', *Diplomatic History* 34, no. 2 (2010): 299–323.

¹⁹ See Margaret Humphreys, *Yellow Fever and the South* (Baltimore, Md.: Johns Hopkins University Press, 1999).

²⁰ For more on eradicationism, see Stepan, *Eradication*.

²¹ Packard, "'No Other Logical Choice": Global Malaria Eradication and the Politics of International Health in the Post-War Era'; Cueto, *Cold War, Deadly Fevers*; Siddiqi, *World Health and World Politics*.

certain Latin American countries, certain regions of Africa, and one area in the USA'.²² Committee members acknowledged the magnitude of the project by declaring that 'this concept of complete eradication of poliomyelitis is a bold one and the whole problem is worthy of the closest study, not only in the field but also at the theoretical level'.²³

The exploration of the possibility of polio eradication through studies did, in fact, begin very soon after the publication of the report. In a paper presented at a WHO training course on poliomyelitis control held in Prague in 1961, Vilém Škovránek, Czechoslovakian Minister of Health, asserted that experiences with nationwide mass vaccination campaigns with the Sabin vaccine 'justify the conclusion that in this way we shall also be able to approach most closely and most rapidly the ideal results of vaccination with live attenuated polio-viruses, i.e. the eradication of poliomyelitis'. This use of the eradication concept was much more than an empty reference to a fashionable idea of the era. In what followed, Skovranek gave a detailed description of what was required in terms of epidemiological data collection, virological examinations, rapid vaccine administration, health services and public communication for what he referred to as the 'final success'.²⁴

Given the discussions among virologists from the late 1950s onwards, the WHO report and detailed plans to study the method with which polio eradication would be possible, it is striking that some twenty years later the disappearance of polio as a result of vaccination with the Sabin vaccine would be 'largely unpredicted', 'never expected' or 'a surprise' to some American researchers.²⁵ One explanation for this could be the limits of internationalism in public health in the Cold War, explored in the previous chapter. While, as we will see below, Eastern European experiences, methods and expertise were actively drawn upon in devising eradication strategies, at the same time they could have been rendered invisible as valid projections or theoretical considerations by Cold War politics. Where disease control opened one gap in the Iron Curtain, Cold War concepts closed another.

Not only did the idea of polio eradication itself emerge in the late 1950s and early 1960s, but so did criticism of the notion. Alongside enthusiasm for the possibility of ridding the world of polio, the idea was also contested in this golden age of eradicationism. Critical voices were already emerging at the

²² Expert Committee on Poliomyelitis, 'Expert Committee on Poliomyelitis. Third Report', 51.

²³ Ibid. 30.

²⁴ Vilém Škovránek, 'Principles of Organization of Vaccination with Live Vaccine with Particular Reference to the Experience Assembled in Czechoslovakia. In Letter from Skovranek, Vilem to Sabin, Albert B. Dated 1961-05-13.' Cincinnati: Albert B. Sabin Archives, Hauck Center for the Albert B. Sabin Archives, 1961, Correspondence, Unsorted, Box 02, File 04 (1961), 1961.

²⁵ Neal Nathanson cited by Muraskin, *Polio Eradication and Its Discontents*, 11.

beginning of the process, and some questioned whether polio eradication was a good idea at all:

Let us remember in all our discussions that the development of attenuated poliovirus vaccines was originally stimulated by the need to prevent paralytic poliomyelitis in North America. In many parts of the world poliomyelitis is both relatively and absolutely less important. It would be a pity in our enthusiasm to rid the world of poliomyelitis if in some countries we encourage a demand for poliovirus vaccines in preference for measures for preventing other diseases of greater economic and human importance.²⁶

These words of 1960, from David Dane of the University of Belfast, might ring familiarly to our ears today. After an unsuccessful trial with the Koprowski vaccine, Dane became a staunch critic of live polio vaccines. His observations have not lost currency over the decades, however. Many critics of the global polio eradication programme have raised similar issues about the money and resources spent on the eradication of a disease that might not be high on the public health agenda for many societies.

At the same time, the elimination and possible eradication of polio took hold. The success of certain national strategies in the 1960s and 1970s became blueprints for the global polio eradication programme later in the twentieth century. Countries that had been among the first to eliminate polio and were consistently using and refining the same vaccination method were particularly suited for contributing to a model of polio eradication. Hungary thus, in several ways, became one of the cornerstones in shaping global polio eradication.

From the initial mass vaccination onwards, immunisation with the Sabin vaccine in Hungary continued to be executed in annual mass campaigns, maintaining the model of the first one: with monovalent vaccines (containing one strain each, Type I, followed by III, then II), each administered on a national scale to children between 2 months and 3 years of age, within a week, four to six weeks apart. The mass campaigns were organised in the winter months to avoid conflict with wild enteroviruses, which might interfere with immunity.²⁷ The Hungarian mass vaccination based its method on previous

²⁶ Dick and Dane, 'The Evaluation of Live Poliovirus Vaccines. Paper Presented at the Conference on Live Poliovirus Vaccines, Washington, 22–26 June 1959', in *Who/Polio/36–44*, at 12.

²⁷ Instead, it was influenza outbreaks in the winter that disrupted Sabin campaigns; therefore in 1977 the annual campaigns were pushed back to the autumn. Hungary conducted mass vaccination campaigns with the Sabin vaccine until 1992, when the vaccination method was modified and the country switched back to the inactivated vaccine. Since then, children in Hungary have been receiving polio vaccine in the form of a combined vaccine as part of their routine immunization. István Dömök, 'A Kampányoltások Időszaka', in *A Gyermekbénulás Elleni Küzdelem*, ed. Rezső Hargitai and Ákosné Kiss (Budapest: Literatura Medica, 1994), 169–78, at 175. Concepción F. Estívariz et al., 'Paralytic Poliomyelitis Associated with Sabin Monovalent and Bivalent Oral Polio Vaccines in Hungary', *American Journal of Epidemiology* 174, no. 3 (2014): 316–25.



Figure 6.1 János Jakus's postcard to Albert Sabin, 24 September 1960. *Poliomyelitis, International Cooperation, Hungary 1959–60. Box 12. File 3.5, University of Cincinnati. Hauck Center for the Albert B. Sabin Archives.* **This image is protected by copyright and cannot be used without further permissions clearance.**

field trials, most importantly the Soviet and Czechoslovakian trials. While in the former, Soviet virologists used both monovalent and trivalent vaccines (containing all three strains), in the trial campaigns, their Czechoslovakian colleagues applied monovalent vaccines exclusively, each four weeks apart.²⁸ By 1960, Albert Sabin referred to the monovalent vaccination at intervals of four to six weeks as being 'regarded as optimum during the cold months of the year in temperate zones'.²⁹

Similarly to state socialist countries in Eastern Europe, the new revolutionary state in Cuba placed emphasis on the prevention of communicable

²⁸ M. P. Chumakov et al., 'Preliminary Report on Mass Oral Immunization of Population against Poliomyelitis with Live Virus Vaccine from A.B. Sabin's Attenuated Strains', in *Live Poliovirus Vaccines: Papers Presented and Discussions Held at the First International Conference on Live Poliovirus Vaccines* (Washington, D.C.: Pan American Sanitary Bureau, 1959), 517–29; V. Skovránek et al., 'Field Trial with Sabin's Live Poliovirus Vaccine in Czechoslovakia 1958–1959', *ibid.*

²⁹ Albert B. Sabin et al., 'Live, Orally Given Poliovirus Vaccine. Effects of Rapid Mass Immunization on Population under Conditions of Massive Enteric Infection with Other Viruses', *JAMA*, no. 173 (1960): 1521–26, at 1521.

diseases, paired with the health education of the public.³⁰ The polio vaccination programme is perhaps the most well-known campaign of this time. National mass vaccination with the Sabin vaccine was adopted in Cuba in 1962, with active Eastern European participation, and Hungarian newspapers kept an eye on the process.³¹ The vaccine arrived from the Soviet Union and Karel Zacek, a Czechoslovakian polio expert, provided support on-site in serological studies and establishing the surveillance system.³² The Czechoslovak expert assessed incident rates in different age groups, and studied the seasonality of the disease. The vaccination programme was then designed with his recommendations in mind, immunising the population between the age of 1 month and 15 years, with the Sabin trivalent vaccine.³³ Zacek also participated in the organisation of the vaccination campaign. He held national and regional lectures on the disease and the oral polio vaccine for health professionals and zone directors, who in turn trained vaccinators, health brigade members and social organization members.³⁴

Cuba became the first populous country to eradicate wild poliovirus in the Western Hemisphere.³⁵ Cuban experiences then became the basis for Latin American National Immunisation Days in the subsequent decades. A notable case in Latin American polio eradication was the introduction of National Immunisation Days (NIDs) in Brazil, which influenced global strategies significantly. Brazil had introduced national immunisation with the Sabin vaccine in 1973, which started with mass vaccinations and was integrated into routine vaccination programmes soon after. However, after an outbreak in 1979 prompted national authorities to change strategy, they introduced 'blanket' vaccination campaigns to be conducted in a short period of time, twice a year.³⁶ Similarly to the Hungarian case, the Brazilian military regime saw an opportunity in the introduction of a national polio prevention campaign to legitimate its rule, which had been marked by political and economic crises at the time.³⁷

³⁰ P. Sean Brotherton, *Revolutionary Medicine: Health and the Body in Post-Soviet Cuba*, ed. Michael M. J. Fischer and Joseph Dumit, *Experimental Futures: Technological Lives*, Scientific Arts, Anthropological Voices (Durham Duke University Press, 2012), 69.

³¹ 'A Gyermekbénulás Elleni Oltást Latin-Amerikában Elsőnek Kubában Vezetik Be', *Népszabadság* 1962, 6; 'Intézkedések Kubában a Gyermekbénulás Megelőzésére', *Népszabadság* 1962, 6.

³² P. Más Lago, 'Eradication of Poliomyelitis in Cuba: A Historical Perspective', *Bulletin of the World Health Organization* 77, no. 8 (1999): 681–87.

³³ Beldarrafn, 'Poliomyelitis and Its Elimination in Cuba: An Historical Overview'.

³⁴ *Ibid.* 34.

³⁵ Smallman-Raynor et al., *Poliomyelitis. A World Geography: Emergence to Eradication*, 519.

³⁶ Nascimento, 'Poliomyelitis Vaccination Campaigns in Brazil Resulting in the Eradication of the Disease (1961–1994)'.

³⁷ André Luiz Vieira de Campos, Dilene Raimundo do Nascimento, and Eduardo Maranhão, 'A História Da Poliomielite No Brasil E Seu Controle Por Imunização', *História, Ciências, Saúde-Manguinhos* 10, no. Suppl. 2 (2003): 573–600.

NIDs as tools of polio control soon spread to Nicaragua, the Dominican Republic and other parts of Latin America. Seen as a success, the Pan American Health Organisation announced a plan of action in 1985, calling on all American countries where polio was endemic to institute NIDs by 1990.³⁸ The method of mass vaccination with the Sabin vaccine was then adopted by China in the early 1990s and, based on the campaign's success there, was extended to the Western Pacific region of the WHO.³⁹

Experiences with the Hungarian, Cuban and Brazilian vaccination programmes thus became the basis for the eradication strategy recommended by the WHO, notably that children under 5 years were to be immunised on National Immunisation Days in two rounds, four to six weeks apart.⁴⁰ One crucial element seems to stand out from the models used in the Global Polio Eradication Initiative well into the twenty-first century: all were implemented by so-called authoritarian regimes. As the concerns surrounding the development and safety of the Sabin vaccine show, Cold War rhetoric and stereotypes regarding political systems played crucial roles in the global evaluation of the Sabin vaccine. Preoccupation with authoritarian political systems in public health management was not new. As early as 1948, at the First International Poliomyelitis Conference, leading British orthopaedist Herbert J. Seddon reflected on the status of polio at the crossroads of the post-war trauma and the progressing Cold War:

At the present time there is more than enough dictatorship in the world and we do not want to add to it. Yet there is no doubt that the cheapest and best way of dealing with poliomyelitis is to have organizations in readiness headed by men of acknowledged competence, who, for a limited time, are permitted a very large measure of authority.⁴¹

Seddon had every reason for phrasing the dilemma with caution. It was only very recently that Nazi Germany had applied the rhetoric and practice of control and eradication to disease and people, connecting medicine and epidemic management with genocide, as historian Paul Weindling has argued.⁴² The rise of the Stalinist Soviet Union and the unfolding Cold War did nothing to appease the very real concerns over authoritarianism and disease control.

³⁸ Jean-Marc Olivé, Joao Baptista Risi, and Ciro A. de Quadros, 'National Immunization Days: Experience in Latin America', *The Journal of Infectious Diseases* 175, no. Suppl. 1 (1997): 189–93.

³⁹ Stepan, *Eradication: Ridding the World of Diseases Forever?*, 238.

⁴⁰ G. J. Ebrahim, 'Polio Eradication, and After... ', *Revista Brasileira de Saúde Materno Infantil* 2, no. 2 (2002), 189–91; Harry F. Hull et al., 'Progress toward Global Polio Eradication', *Journal of Infectious Diseases* 175, no. Supplement 1 (1997): S4–S9.

⁴¹ Herbert J. Seddon, 'Economic Aspects of the Management of Poliomyelitis', in *First International Poliomyelitis Conference* (New York: Lippincott, 1948), 35.

⁴² Paul Weindling, *Epidemics and Genocide in Eastern Europe, 1890–1945* (Oxford and New York: Oxford University Press, 2000).

The merit of certain autocratic measures in successfully preventing or treating disease and its increasing connection with Cold War ideas of democracy and autocratic rule became a recurring issue in the history of polio. It played a crucial part in the evaluation of the Sabin vaccine's potency and safety based on the early and massive trials conducted in the Soviet Union by Dorothy Horstmann. Cold War stereotypes and frustrations with autocratic measures persisted until the end of the disease. After their success in actually eliminating polio quickly and effectively, Eastern European and Latin American methods transitioned into models used worldwide, seemingly without many problems, deliberations or concerns.

The models of Hungary and Cuba continued to be used in global polio eradication campaigns in other ways. The mass vaccination campaigns of these countries not only proved to be highly efficient in suddenly ending polio, but the vaccination method, along with the vaccines, continued to be constant for decades. This stability was partly guaranteed by the political system in these countries and has been drawn upon for research on polio eradication well into the twenty-first century. Moreover, once polio epidemics ended and the disease became a rarity, the monitoring system seems to have functioned reliably. This was most probably the achievement of internationally acclaimed virologist István Dömök, who started working at the virology department of the State Hygienic Institute of Hungary in 1961 and was the organisation's director from 1973 onwards. Furthermore, the rarity of polio in Hungary after 1960 permitted a system where all suspect cases could be treated centrally, and thus monitored and assessed more easily.

One of the biggest challenges for polio eradication with live poliovirus vaccines has been the presence of vaccine-associated paralytic polio (VAPP) from vaccine-derived poliovirus (VDPV), discussed in more detail in the previous chapter. As mentioned earlier, polio cases did not disappear in Hungary after the end of outbreaks: over three decades, dozens of vaccinated children became paralysed by polio contracted from the vaccine. The rate of VAPP in Hungary was high in international terms: almost seven to eight times as high as in the United States and almost three times as high as in East Germany.⁴³

The country's virological and public health history thus became terrain for study in the late twentieth and early twenty-first centuries when collecting information for the endgame of the global polio eradication programme and attempting to solve the dilemma of OPVs, which were both best suited for eradication and the only tools through which polioviruses could not disappear

⁴³ Estívariz et al., 'Paralytic Poliomyelitis Associated with Sabin Monovalent and Bivalent Oral Polio Vaccines in Hungary'.

from the world. As Victor C aceres of the CDC and Roland Sutter of the WHO Polio Eradication Campaign put it:

[T]he best data on VAPP caused by MOPV comes from Hungary, where these strains have been used the longest. D omk described the experience in Hungary where for >20 years MOPV had been delivered through biannual mass campaigns to children between 2 and 38 months of age. These campaigns effectively eliminated indigenous transmission of wild poliovirus. Hungary had maintained an excellent surveillance system for poliomyelitis since 1966, requiring that every patient with suspected poliomyelitis be admitted to the Central Hospital for Infectious Diseases in Budapest, for thorough clinical and laboratory evaluation. Therefore, in Hungary there existed these unique conditions: (1) a largely susceptible birth cohort; (2) absence of ‘confounding’ protection from previous exposure to wild poliovirus strains; and (3) an excellent surveillance system.⁴⁴

Reviewing Hungarian vaccination data and VAPP cases became important once again after 2005, as the Global Polio Eradication Initiative moved away from trivalent OPV (Sabin vaccine containing all three poliovirus strains) to monovalent (containing one strain) and bivalent (containing two strains) vaccines. Wild poliovirus Type II disappeared from circulation in 1999, and the Global Commission for the Certification of Poliomyelitis Eradication announced its global eradication. Since monovalent and bivalent (containing Type I and Type III) were found to have higher efficacy, the GPEI started shifting to the use of these vaccines.⁴⁵ The question now was the risk of monovalent polio vaccines causing VAPP. Since the monovalent Sabin vaccine had been used in Hungary from 1961 through 1991, a team of researchers from the CDC, WHO, Bill and Melinda Gates Foundation and Hungarian public health institutes analysed Hungarian historical epidemiological and virological data, along with that of other Eastern European countries and the former Soviet Union, to assess the risks of monovalent vaccine use in the twenty-first century.⁴⁶

The fact that the country was among the first to introduce a national mass vaccination programme, along with the abrupt end of polio that the campaign brought, the consistent use of the same vaccination method and a surveillance system that was considered to be reliable, meant that Hungary became a model for polio eradication, both in exploring potential problems, such as VAPP and VDPV, and in providing a method for efficient disease control. This model, as we will see, was restrictive. With the end of polio in Hungary, focus on

⁴⁴ C aceres and Sutter, ‘Sabin Monovalent Oral Polio Vaccines: Review of Past Experiences and Their Potential Use after Polio Eradication’.

⁴⁵ Chris Maher, interview by D ora Vargha, 2012.

⁴⁶ Est ivariz et al., ‘Paralytic Poliomyelitis Associated with Sabin Monovalent and Bivalent Oral Polio Vaccines in Hungary’.

medicine, public health and state services shifted to prevention, which soon became the exclusive point of engagement with what was a complex disease.

Local Consequences: Endings from Below

With no new polio cases in Hungary, in 1963, just seven years after it was established, the Heine-Medin Hospital was turned into a general children's hospital. Polio patients were sent home, and the staff were retrained or disbanded. It was as Katalin Parádi had feared: the majority of patient files she had so carefully prepared were lost in the administrative jumble of state socialist Hungary.

This lack of access to their own medical history made life difficult for many children growing up with polio, since the details of their previous surgeries, orthopaedic needs and prescriptions were all lost. Fortunately, Katalin had the foresight to keep the originals in the archives of the new hospital, where she continued to work, and she was happy to make further copies for anyone who requested. This did not help the majority, some of whom were treated in other institutions and many of whom probably did not know about the central archive of records. Furthermore, access to these archives ceased long before the need for them ended: when Katalin Parádi retired, she lost control over the boxes that contained the patient files.⁴⁷ The files disappeared, leaving patients struggling with post-polio syndrome in a difficult position.

What happened to the patient files is unclear. Current hospital staff say that they were moved to a mouldy basement that is now hazardous to health and is closed off from public use. According to archivist rumour, the basement, also known as the 'spidery', is not hazardous, but records are not there. Perhaps they were destroyed during an administrative takeover of old hospital buildings in the post-socialist era. The fate of the files once more demonstrates the disorganization and ineffectiveness that coexisted with centralized and efficient structures within the socialist state, even within the sphere of public health.

The ways in which the proclaimed end of a disease can be exclusionary and the ways certain people are left out of the narrative come to light through the story of Hungarian polio survivors. As vaccination with the Sabin vaccine put an end to polio epidemics, the state lost interest in polio on the whole, treatment centres were dismantled, and the medical and educational care of children with polio withered away. As the state pulled away from polio – a disease that no longer threatened its population – patients whose lives were untouched by the benefits of vaccination found their care to be

⁴⁷ Parádi, interview by Vargha, 27 January 2010.

determined more by their geographic location and social status than ever before. Many children returned to their families; those with the financial means could continue physical therapy in their homes. Others, who did not have families or whose families could not or did not want to care for them, continued living in secluded institutions. Some of these children were abandoned when they were first diagnosed with polio, while others could not return to their parents, who lived in excessive poverty and often worked long hours as day labourers.⁴⁸

Perhaps the most striking change that the end of polio caused was in the lives of children left in institutions, partly because of the excessive poverty of their families. A large group of institutionalised children with polio no longer received medical treatment. Since the state did not allocate an adequate building for their care, the large group of children was shuffled from institution to institution across the country. Similarly to the Romanian practice of housing disabled children, these sites were often castles and palaces once owned by the aristocracy. The buildings were usually in a derelict state, having been used as warehouses or stables by passing armed forces during the war. These sites were far from cities, and their location contributed to the exclusion and neglect experienced by some of the children.⁴⁹ Remembering this time, some former patients jokingly called this part of their lives the 'travelling circus'.⁵⁰

Their life was partly determined by the location where they ended up each year. Although living in seclusion, the children forged lifelong friendships, attended beat concerts, sneaked out to parties and, in their teenage years, to each other's rooms for romantic or sexual encounters. Some institutions were worse than others: of the years of travelling year after year 'from border to border' in uncertainty,⁵¹ the most traumatic memory was their stay in a mental asylum. Here, the children shared corridors with adult mental patients who were often restrained and 'screamed at night'.⁵²

This structuring, or rather un-structuring, of polio care was a huge break with the paternalistic practice of centrally organised, institutional social and medical care. Access to specialised care ceased for children living outside the capital. Delegating specialist care to local district general practitioners, who often lacked the funds, time or expertise to care for children with polio, as well as the complete lack of any medical care in the depository institutions, deprived children of important and significant resources that had been

⁴⁸ Franciska Kormos, *Magánkeringő* (Budapest: Aposztróf Kiadó, 2010).

⁴⁹ Maria Roth, 'Child Protection in Communist Romania (1944–1989)', in *Social Care under State Socialism (1945–1989). Ambitions, Ambiguities and Mismanagement*, ed. Sabine Hering (Opladen and Farmington Hills: Barbara Budrich Publishers, 2009), 201–11.

⁵⁰ Julianna Bedő, Tamás Kertész and Tibor Szabó, 'Interview', *Hévíz* 2010.

⁵¹ Kormos, *Magánkeringő*, 107.

⁵² Bedő, Kertész and Szabó, 'Interview'. Also see Kormos, *Magánkeringő*.

available to them before polio ended. The absence of children with polio in visual representations, paired with their absence from society due to the seclusion of their treatment, then took on an even greater invisibility. Polio patients disappeared from the concerns of state healthcare and from the pages of medical journals. Their care was no longer organised and their needs – medical, social, emotional and material – were not addressed.

The end of polio in Hungary also contributed to the end of knowledge about the disease. Polio treatment was no longer taught in medical schools. Since most physicians and physical therapists who practised in the 1950s and early 1960s have died, knowledge of polio treatment can be found in a handful of publications collecting dust in the depths of the National Library of Hungary. This problem is not a local one: a recent American and British study on polio survivors notes that ‘the vast majority of physicians and other healthcare professionals working in developed countries in the post-vaccine era have never encountered a case of polio and thus often lack experience and understanding of the treatment and long-term pathology of the disease’.⁵³

Through interviews with people living with polio, however, it has become clear that knowledge about treatment has not entirely disappeared. Rather, its site has changed: it is the patients themselves, many battling post-polio syndrome, who are in possession of medical knowledge regarding their own treatment. They know the exact equipment (e.g. shoes, crutches, braces) they need, and some have a very clear idea of exactly what corrective surgery their limbs require. Yet the expertise and prescriptions of primary care physicians and specialists are needed for their special equipment, vouchers for physical therapy and operations. Accepting complete authority in treatment from patients is often problematic for many doctors, and some patients have recounted bitter battles with physicians and surgeons over the course of action to be taken. Others have had more positive encounters, where their expertise on polio was acknowledged and the physician was ready to take notes from them. But polio patients themselves sometimes do not have much information about their own condition. Many were small children at the time of their operations and treatment, and since many of the patient records have been lost or are unrecoverable, they have no access to knowledge of the kinds of medical interventions they were exposed to. Most polio patients first learned about post-polio syndrome at a polio convention in 2010, through translations of American brochures.

In this sense, the end of polio in Hungary is a case in agnotology: the cultural production of ignorance and forgetting, as Robert Proctor and Londa

⁵³ Nora Ellen Groce, Lena Morgon Banks, and Michael Ashley Stein, ‘Surviving Polio in a Post-Polio World’, *Social Science & Medicine* 107, April (2014): 171–78, at 174.

Schiebinger have described.⁵⁴ Medical knowledge and practice of the disease did not vanish because there was no need for it anymore. The elimination of polio from the country did not directly change the condition of patients who already had the disease, but it did eliminate polio from the priorities of health and population policies. Through this elimination, polio patients, their bodies and the scientific knowledge their treatment required became invisible in the eyes of the state, the public and the medical profession. Polio patients kept on living after the end of polio, a life that was now mostly determined by a disease that was no more.

One group of patients was *not* expected to keep on living, though.

Some patients – children and adults alike – saved from death by suffocation with the help of long-term mechanical ventilation during the acute phase of poliomyelitis could not be freed from the use of respirators later on either, due to the paralysis of respiratory muscles. It is through them that we could learn the concept and reality of chronic respiratory paralysis – a human condition. Our aim here is to describe this new human life form.

This is how the head of the Hungarian respiratory ward begins her habilitation thesis titled ‘The fate of polio patients with respiratory paralysis kept alive by long-term mechanical ventilation’. The objects of her study were people living in or with respiratory machinery like iron lungs for decades after the epidemics of the 1950s.⁵⁵

Since the lives of patients with respiratory paralysis were physically bound to heavy machinery, the Heine-Medin Hospital’s iron lung ward was the only one that remained primarily focused on polio care after 1963. For the next few decades, access to continuous care in the framework of the socialist healthcare system, paired with lack of resources, created a community in the respiratory ward that challenged concepts of childhood, families and conventions in terms of medical knowledge and caretaker roles. Medical staff assumed parental duties, nurses worked with highly specialised medical knowledge and also doubled as technicians and children became active participants in shaping their own treatment.

In a setting where the provider role of the state overrode individual responsibilities for health and care, there was no pronounced goal of integrating respiratory polio patients in society and sending them home. Medical care was free and institutionalised. There was no financial incentive for the families of patients for home care, which would have required significantly more funds and constant family member care. Moreover, the ideology of state paternalism,

⁵⁴ Robert Proctor and Londa L. Schiebinger, *Agnology: The Making and Unmaking of Ignorance* (Stanford, Calif.: Stanford University Press, 2008).

⁵⁵ Dr Kiss, ‘Tartós Gépi Lélegeztetéssel Életben Tartott Postpolió Lézésbénultak Sorsa’.

which significantly formed medical treatment at this time, further contributed to the lifelong hospital stay of many of these patients.

This institutionalisation also meant that the children, and later adults, who spent their lives connected to respiratory machines were viewed almost exclusively through a medical and scientific lens. The community of iron lung and respiratory patients was constantly observed by the staff, occasionally by sociologists, and their lives were the focus of medical publications and psychological studies.⁵⁶ The bodies of the patients and their coexistence with intricate machinery were perceived in terms of infections, complications, possible malfunctions and endangerment by power outages and were managed with further technological interventions such as suctioning and measuring (level of oxygen content, temperature, muscle activity, etc.). At the same time, the social and emotional care of the patients, from combing their hair to reading to them, as well as resolving conflict among room-mates over the use of the radio, also became part of the everyday tasks of the medical staff.⁵⁷ Respiratory patients thus transformed the professions of their carers. Nurses became highly skilled technicians, who could fix the machines on a whim, but also provided social and emotional work. Physicians had to reconsider their roles and their ideas of healing, as the management of these chronic patients excluded the possibility of improvement.⁵⁸ Chronic care ended with the death of the patients, many of whom had spent their entire lives from early infancy as objects of medical attention – eternal patients.

Living with respiratory technology was a wholly new experience for patients and physicians alike: ‘There was no medical precedent for this. As far as we knew, these children could live one, two or three years in iron lungs or other respiratory devices’, remarked the director of the ward.⁵⁹ As time went by, it became clear that these children would not only survive for a few years, but would also actually grow up with the help of respiratory technology. Thus, the concept of a ‘new human life form’ was created, one that did not exist without machines.

Medical professionals and parents alike were unprepared for what was to come, since nobody really knew what was to come at all. Bodies that could not be separated from machinery, at least not for a significant time, and could not exist without mechanical breathing, blurred the boundaries between machine

⁵⁶ Anna László, *Vaspólya* (Budapest: Szépirodalmi könyvkiadó, 1979); Ákosné Kiss, ‘Légzésbénult Utókezelő Osztályon Szerzett Tapasztalataink’, in *Előadások a Gyermekbénulás Rehabilitációs Problémáiról*, ed. László Lukács (Budapest: Statisztikai Kiadó, 1961), 47–53; Dr. Kiss, ‘Tartós Gépi Lélegeztetéssel Életben Tartott Postpolió Légiésbénultak Sorsa’.

⁵⁷ László, *Vaspólya*.

⁵⁸ Dr. Kiss, ‘Tartós Gépi Lélegeztetéssel Életben Tartott Postpolió Légiésbénultak Sorsa’, 1989; Mészáros, interview by Vargha, 11 January 2008.

⁵⁹ Ádám Csillag, ‘Gyermekbénulás II’, Csillag és Ádám Film; Fórum Film, Hungary, 1995.

and man, but also between the bodies of the patients and the bodies of others. Since many of the patients were completely paralysed, every activity required another, mobile body – that of a nurse, a doctor, a relative or a visitor. The boundary between body and machine and the concept of life itself became extended to and inseparable from other bodies and lives.

This ‘new life form’ also challenged ideas of the life cycle.⁶⁰ At first, expected to last no more than a few weeks or months, life turned into years, extending without expectation, ending at various times. There was no ‘life expectancy’ set for these patients. Some lived to 60, others died from complications of minor surgery at the age of 20. The lack of a foreseeable life cycle also blurred the concepts of childhood and adulthood and questioned its definitions. Respiratory patients and physicians directing their everyday lives had different ideas about their life cycle. As respiratory polio patients got older, more and more frustrations arose in the ward. Patients complained about the strict regulation of their lives, from the use of the telephone line to their decisions about their preferences of consumption, while physicians complained about patients’ disregard for their own medical conditions and their pestering of the medical staff.⁶¹ The increasing conflict in the ward and frustration on both sides (patients and carers) points to different definitions and perceptions of where childhood ends, where adulthood begins and what adulthood, independence and decision-making means at all, for those who in life and body were extended and entangled.

In sum, the life form of iron lung patients raised questions about the definitions of human life. They contested boundaries – of bodies, machines, medicine and care, life cycles. As they were unprecedented, they also revealed the preoccupation with the upcoming unknown. In the post-war context of the terrible experience of dehumanisation in the recent past on the one hand, and a strong belief in the technological and scientific progress of the future on the other, the issue of terming polio patients living with respiratory technology new life forms is an important one.

Respiratory patients in this sense were not seen as disabled, but as humans who could not be fitted into the concept of human life as it was known. This

⁶⁰ Sophia Roosth and Stefan Helmreich in their article ‘Life forms: A Key Word Entry’ provide an analysis of the term and concept through two centuries. They describe a shift in the twentieth century in the meaning of the term from archetype to future types. Life forms become relegated to the realm of science fiction and of the future. While Roosth’s and Helmreich’s work focuses on the term in English language and its German origins, their observations can be useful in thinking about iron lung patients in other linguistic and cultural contexts. In the case of Hungarian respiratory patients life form was at once a present challenge, due to the cutting edge technology a stuff of science fiction, and a constant reflection on the future. Life in this form was re-evaluated and constantly gained new meanings. Sophia Roosth and Stefan Helmreich, ‘Life Forms: A Keyword Entry’, *Representations* 112, no. 1 (2010): 27–53.

⁶¹ László, *Vaspólya*.

perception could simultaneously be liberating and highly discriminating. By being termed as ‘new life forms’, polio patients as hybrids and cyborgs were, at least at times, free to bend boundaries and set up whole new rules and laws governing their own and their extensions’ lives. However, the demarcation between us and them also had grave and long-lasting consequences. Perceived as profoundly different, patients found themselves excluded from any effort at integration, be it finding a job, establishing a family or choosing their friends. One patient, after earning a degree in philosophy, had to make a living by assembling flashlight key rings. A female patient had to endure remarks from strangers while in labour about why ‘these’ (not even people, not things) had to reproduce themselves. A third patient, at the age of 50, still dreamt of becoming an engineer one day.⁶²

A Civil Movement in State Socialism

Former polio patients are very much aware of the effect that the end of the disease has had on them and society. They widely refer to themselves as ‘dinosaurs, a breed that is about to become extinct’.⁶³ While usually spoken in jest, this recognition of being among the last in society with the condition is also paired with a sense of pride at belonging to a unique community. There is reason enough for this pride, since in the early 1980s former polio patients achieved the unthinkable in state socialism: the organisation of a civil society that was not initiated or co-opted by the state, nor based on political dissent.

As Eastern European disability scholars, such as Elena Iarskaia-Smirnova and Michael Rasell, have pointed out, historical accounts of Eastern European disabled persons have mostly discussed disability in terms of oppression and neglect and rarely considered disabled people as active agents.⁶⁴ Even fewer have connected disability to civil society in the Eastern Bloc.⁶⁵ Histories of activism and grassroots organisation in Eastern Europe have exclusively focused on political dissent, and most often on its intersections with culture: from broader discussions of intellectual self-organisation⁶⁶ to taking samizdat (underground publishing) and tamizdat (publishing abroad) as a starting

⁶² Csillag, ‘Gyermekbénulás II’. ⁶³ Bedő, Kertész, and Szabó, ‘Interview’.

⁶⁴ Michael Rasell and Elena Iarskaia-Smirnova, *Disability in Eastern Europe and the Former Soviet Union: History, Policy and Everyday Life*, Bases/Routledge Series on Russian and East European Studies (London and New York: Routledge, Taylor & Francis Group, 2014).

⁶⁵ Baár, ‘Disability and Civil Courage under State Socialism: The Scandal over the Hungarian Guide-Dog School’.

⁶⁶ Detlef Pollack and Jan Wielgoths, *Dissent and Opposition in Communist Eastern Europe: Origins of Civil Society and Democratic Transition* (Burlington, VT: Ashgate, 2004).

point,⁶⁷ or counterculture and flourishing underground music in the 1980s.⁶⁸ Some scholars of dissent and opposition have gone as far to argue that 'genuine' civil society did not and could not exist at all in state socialist Eastern Europe.⁶⁹

But twenty years after mass campaigns with the Sabin vaccine brought about the disappearance of polio epidemics and, with it, the abandonment of people living with the eliminated disease, a civil society did emerge, one that was united not by political dissent, but by disability. Rather than opposition to the political system, this movement was a product of it: its birth had much to do with the particularities of state paternalism and the responsibilities and expectations shared among citizens and the state. In the eyes of the ageing polio patient generation, the communist state had not fulfilled its role and had failed to provide for them as promised.

Institutionalised children and others relegated to professions like shoe or watch repair grew up with very limited life choices. Many of them share the bitter view that the state abandoned them and destined them to poverty as adults by not providing adequate education in their youth.⁷⁰ For some, this experience prompted a realisation that they needed to become proactive, developing an attitude that was not usual in state socialism. In the late 1970s, drawing on the network developed during their long hospital stays, young adult polio patients established something unimaginable and unique in a communist state: a civil association that was wholly divorced from Party politics and from dissent. 'We realised that nobody was going to help us, so we needed to help each other',⁷¹ recalls one of the founding members of the National Association of Disabled Societies.

The disabled adults utilised the network they had built during their long hospital stays and also took advantage of the fact that the concept of private data had not taken hold in healthcare. Volunteers, some of whom had worked in the medical profession previously, contacted hospital administrations and obtained the list of polio patients treated there in the 1950s and 1960s, along

⁶⁷ Friederike Kind-Kovács and Jessie Labov, *Samizdat, Tamizdat, and Beyond: Transnational Media during and after Socialism*, Studies in Contemporary European History (New York: Berghahn Books, 2013).

⁶⁸ Anna Szemere, *Up from the Underground: The Culture of Rock Music in Postsocialist Hungary*, Post-Communist Cultural Studies Series (University Park, Pa.: Pennsylvania State University Press, 2001). Thomas Cushman, *Notes from Underground: Rock Music Counterculture in Russia*, Suny Series in the Sociology of Culture (Albany: State University of New York Press, 1995); Trever Hagen, 'From Inhibition to Commitment: Configuring the Czech Underground', *Eastbound*, no. Down to the Underground: Popular Music and Society in Central Europe, ed. Trever Hagen, Tamás Tófalvy and Gábor Vályi (2012), 1–34.

⁶⁹ Matt Killingsworth, *Civil Society in Communist Eastern Europe* (Colchester: ECPR Press, 2012).

⁷⁰ Ágnes Soós, 'Interview' (Budapest 2010); Bedő, Kertész, and Szabó, 'Interview'.

⁷¹ Kálmánné Gere, interview by Dóra Vargha, July 2007.

with their phone numbers and addresses.⁷² This way, they even managed to find people who had been isolated from the polio community beforehand, and had lived their whole life alone with their disability.⁷³ By 1979 there were six regional associations, which established the Cooperative Committee of Disabled Associations to coordinate the associations and represent them in interactions with the state. By 1980, the number of participating associations rose to ten, and the plan was to establish an association for each of the country's nineteen counties.⁷⁴

Getting the Party's approval for such an enterprise was a more difficult matter. The initial response from the government was total rejection and it took over two years of negotiation through political connections to receive authorisation for the founding of the national association.⁷⁵ The turning point came in 1981, which was proclaimed 'International Year of Disabled Persons' by the United Nations.⁷⁶ The General Assembly adopted the resolution of the International Year in 1976, setting the theme as 'full participation'.⁷⁷ The goal of the International Year was for disabled people 'to participate fully in the social life and development of their societies and to enjoy living conditions equal to those of other citizens, as well as an equal share in the improvements in living conditions resulting from social and economic development'.⁷⁸

In Hungary, unsurprisingly, it was through capability to work and the functioning of social services, especially rehabilitation, that full participation was perceived.⁷⁹ Accordingly, it was the Ministry of Labour that became responsible for coordinating the International Year. Disability had not received so much attention since the end of polio epidemics. Yet the involvement of the Hungarian government in the global programme was less than enthusiastic. The Council of Ministers decided that there would be no international event organised and that keeping costs low should be a priority.⁸⁰ Socialist brigades, institutions and youth organisations raised funds for the support of the disabled in the country. Several new rehabilitation institutes were built and three holiday camps were made accessible to disabled children. There was an

⁷² Vargha, interview by Vargha, 15 June 2008. ⁷³ Gere, interview by Vargha, July 2007.

⁷⁴ *Fogyatékoság-Politikai Szakismeretek Fogyatékoságtudományi Tudásbázis* (Budapest: Eötvös Loránd Tudományegyetem Bárcsi Gusztáv Gyógypedagógiai Kar, 2009).

⁷⁵ Lajos Hegedűs, interview by Dóra Vargha, April, 2010.

⁷⁶ United Nations General Assembly, 'International Year of Disabled Persons, U.N. Doc. A/Res/36/77 (1081)' (University of Minnesota Human Rights Library, 1981).

⁷⁷ '31/123. International Year of Disabled Persons. Resolution Adopted by the General Assembly', in *A/RES/31/123* (New York, 1976).

⁷⁸ '35/133. International Year of Disabled Persons. Resolution Adopted by the General Assembly', in *A/RES/35/133. Thirty-fifth Session, Agenda item 79* (New York, 1980).

⁷⁹ Judit Csehák, 'A Foglalkoztatási Rehabilitációról – a 'Rokkantak Nemzetközi Éve' Után', *Népegészségügy* 63, no. 3 (1982): 129–36.

⁸⁰ 'A Rokkant Személyek Nemzetközi Évéhez Kapcsolódó Feladatok.' Budapest: Magyar Nemzeti Levéltár, Minisztertanács Jegyzőkönyvek, 288.f.7., 604. ő.e., 1980.

increase in the representation of disabled people in television and radio as well, in order to promote the integration of the disabled into society.⁸¹

Most steps taken in the framework of the International Year of Disabled Persons were superficial and did not have lasting effects, save one. It was this interest generated by the United Nation's global programme that created the opportunity for polio patients to take their association to a national level. The first, founding assembly of the National Association of Disabled Societies, coordinating nineteen regional organisations, was held on 13 June 1981. The Association, whose leadership (and the majority of its membership) is still made up of former polio patients, has been a major force in pushing for disability and accessibility laws; has founded a small packaging company to provide work for members and income for the organisation; and has also fulfilled a social function in organising meetings for former patients to connect or reconnect.

The activism of polio survivors and the origins of the National Association of Disabled Societies, whose leadership is still made up primarily of people disabled by polio, were prompted by the end of epidemics and the official end of polio in Hungary. Their story is not entirely unique, however, and points to the ways in which we need to revisit our understanding of Cold War societies. Historian Monika Baár has explored the self-organisation of the blind in Hungary in the 1970s, through the story of the guide dog school. In her analysis, she shows the similar starting points of the paternalist state and the 'welfare dictatorship': an implicit social contract in which the state takes on the responsibility of providing social and economic security in return for political compliance. In this sense, welfare provisions function as a legitimisation of the state's power.⁸²

It was this social contract that polio patients saw was broken, which in turn prompted them to organise themselves and provide for each other, as well as to enforce the social responsibilities of the state. The examples of the National Association of Disabled Societies and the guide dog school show that on the one hand, we cannot dismiss Eastern European countries as exclusively oppressive and abusive towards the disabled, with no space for resistance, negotiations and activism. In turn, a wealth of disability history attests to exclusions, neglect and inequalities in Western societies as well. More broadly, these histories can contribute to an understanding of civil society that may work in a variety of ways, some more organised and visible, some practising direct influence, albeit tacitly.

⁸¹ 'A Foglalkoztatási Rehabilitációról – a 'Rokkantak Nemzetközi Éve' Után'.

⁸² Baár, 'Disability and Civil Courage under State Socialism: The Scandal over the Hungarian Guide-Dog School'.

On the one hand, the end of polio in Hungary meant the end of medical care and the beginning of abandonment for thousands and thousands of children, who were already stricken with polio at the time of disease elimination. On the other, this abandonment by the state that had built itself on the role of the provider and paternal care prompted something that had been thought to be impossible in communist countries: a grassroots civil society.

The Hungarian case tells us a much broader story about the changing meanings of the disease. One could argue that what happened in Hungary after the end of polio was merely a shift from the acute to the chronic. In many ways, that is true, and prompts the question of whether we are then talking of two different diseases (epidemic polio and polio as a condition). But there is more to it: what remains behind is the uncomfortable lingering presence of the past. In the case of polio, it is an extremely visible legacy that changes from a weapon in combating the disease to invisibility.

The end of polio in Hungary highlights the fact that global disease prevention programmes cannot be divorced from the local politics of prophylaxis, and furthermore that they also cannot be separated from disease treatment and the long-term social, cultural and political consequences of ending a disease.⁸³ The end of the disease in Hungary had a significant impact on the epidemic management of polio on a global scale, both in shaping international scientific debates on vaccine efficacy and safety through the results of the Salk and Sabin vaccines and in serving as a model for global eradication programmes. In turn, international cooperation in vaccine development, the speedy and successful introduction of the Sabin vaccine and Hungary becoming polio-free had profound effects on society, by making disability invisible, and on the lives of thousands who still had a full life ahead of them to live with the disease.

Hungary becoming a model both in terms of socialist public health management and in global polio eradication rested on a particular concept of the end of polio: the end of epidemic outbreaks and transmission of wild polio viruses. With the global eradication campaign stepping up in the 2000s, the image of the end of polio has been reinforced through billboards showing how close the world is to ending polio, the celebration of the eradication of Type II polio virus and the reduction of countries where wild polio is still present from 125 in 1988 to just three twenty-five years later.

The focus on disease elimination and the dominant interpretation of the end of polio also changed what polio as a disease itself was. Through the narrative of the successful end to the disease and the eradication of polio, it increasingly became reduced to a virological phenomenon. The disease's bodily

⁸³ For a Latin-American and Iberian approach to the problems raised with the end of polio, see Juan Antonio Rodríguez-Sánchez, 'Poliomyelitis after Poliomyelitis: Lights and Shadows of the Eradication. An Introduction', *Hygiea Internationalis* 11, no. 1 (2015): 7–31.

manifestation and its social, cultural and political existence have been pushed to the background, turned invisible or disappeared entirely. Accordingly, the complexity of what polio is was not incorporated into the models of the end of the disease, and polio-stricken bodies and lives have not figured in the end-game strategies of the global eradication campaign.⁸⁴

There are broader implications. Eradication may be the ultimate 'end' to a disease, but the epidemic narrative is very much present in many other health issues, from obesity to cancer. And the dramaturgy of increasing tension, crisis and closure is seductive, especially regarding the end. We all yearn for a happy ending, or at least an ending of some sorts, when it comes to diseases that challenge our faith in medical knowledge and our political systems and tear the social fabric.

Hardly anyone would contest that eradicating smallpox was a good idea, or argue that we would rather have polio epidemics back. Furthermore, the narrative can be constructive in more than one way. Epidemics and diseases more generally leave behind not just survivors, but public health practices and structures – not everything is always forgotten or works in exclusionary ways.

At the same time, the end of disease, may it be a goal or wish, or a thing of the past, is often perceived in a particular and narrow sense. Whether it is modernist projects that do not allow for complicated and messy endings (or their lack), or certain diseases themselves that fail to map onto the narrative, endings hardly mean that the story is finished. Therefore, the epidemic narrative can be as deceptive as seductive. To add one more example, the absence of vaccine-preventable diseases and their disappearance from societies have wide-reaching and severe consequences, as the death of an eight-year-old who caught diphtheria in Spain in 2015 reminds us – not just about the rise of anti-vaccination movements, but also about the lack of therapeutic interventions in public health systems for those diseases.⁸⁵

Epidemics may go out with a bang – or a whimper. What the Hungarian case shows us is the importance of investigating what that end is: for whom it comes and does not come; who is rendered invisible by it; what the end itself means to societies, global health policies and individual lives; and how it makes us think past the epidemic narrative.

⁸⁴ Olen M. Kew et al., 'Vaccine-Derived Polioviruses and the Endgame Strategy for Global Polio Eradication', *Annual Review of Microbiology* 59 (2005): 587–635; Global Polio Eradication Initiative, *Polio Eradication & Endgame Strategic Plan 2013–2018* (Geneva: World Health Organization, 2013).

⁸⁵ David Bryan and Dora Vargha, 'Los Antivacunas Y El Pasado Fascista De España', *El País*, 12 June 2015.