

# The Truth Within: Making Medical Knowledge in the Hay Fever Association of Heligoland, 1899–1909

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**Abstract:** Around 1900, hay fever was a contested illness, mostly unknown among physicians or believed to be neurotic in nature. Motivated by a desire to gather and disseminate knowledge about their enigmatic ailment, hay fever sufferers organized to form the Hay Fever Association of Heligoland. The organization’s annual reports combined news from the latest medical science with observations of the illness as experienced by the members of the association. While employing observational practices derived from scientific settings in recording and documenting their suffering, the organized hay fever patients also used subjective experience to challenge the results from professional medical scientists. This struggle between scientific and embodied knowledge sheds new light on the emergence of patient advocacy.

In 1876 Otto Schultz, a wine merchant from Hanover, returned from a trip to Italy in poor health. He experienced pain in his forehead, sore eyes, and extreme sneezing. Every year these symptoms would reappear in the early summer, causing him much distress. Doctors could provide no relief, apart from recommending a recuperative vacation on the East Frisian island of Norderney. On his way there, traveling by ship, Schultz noticed that his symptoms suddenly disappeared. But when he arrived and went strolling in the fields, the suffering started again. From this, he drew the conclusion that “if sea air heals, and field air hurts, I shall go where there is as much sea and as little field as possible . . . that is, to *Heligoland!*”<sup>1</sup>

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<sup>1</sup> Theodor Albrecht, Gotthold Fuchs, and Otto Schultz, *Bericht X des Heufieberbundes von Helgoland nach den Mitteilungen von Heufieberkranken und nach wissenschaftlichen Schriften* (Heufieberbund von Helgoland, 1908), p. 57: “Hilft Seeluft, und

After selecting Heligoland as the place for his annual escape from “field air,” Schultz went on to form the first European patient organization, the Heufieberbund von Helgoland—Hay Fever Association of Heligoland—in 1897. Over the following decades, this organization mobilized its members to observe, record, and report the symptoms of their shared illness and presented this data in annual reports containing advice for treatment and other coping strategies. The association’s objective was to make hay fever a known and accepted diagnosis, particularly within the medical sphere, so that an effective treatment might eventually be found.

Patient organizations today make up a vast and diverse panorama, ranging from very small, informal groups to large, thoroughly professionalized associations. Opinions differ regarding their genealogy and what the term “patient organization” should encompass. Nineteenth-century mutual aid societies and lay associations devoted to particular health-care regimes and remedies might, for instance, be considered patient organizations. Usually, however, researchers have located the roots of today’s patient organizations in the 1960s and assumed a link to other “new social movements” that emerged around that time.<sup>2</sup> Thus understood, patient organizations are bodies that organize people in their capacity as patients and direct their efforts toward the medical realm. In doing so, patient organizations have used the idea of the informed consumer acting in a free market to reframe the patient role and equip it with the right to make an informed choice in matters of health and medicine.<sup>3</sup>

However, a historiography that views patient organizations in the context of either consumer culture or the new social activism from the 1960s onward fails to address the fundamental conditions that enabled patient organizations to form in the first place. Certainly, some patient organizations were closely related to other late twentieth-century political movements, such as the breast cancer movement’s relation to second-wave feminism and HIV/AIDS activism’s relation to gay rights.<sup>4</sup> Nevertheless, a number of different organizations by and for patients formed in Europe and North America before World War II.<sup>5</sup> Since the timing of such organization was removed from the context of late twentieth-century politics and consumerism, it

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schadet Wiesenluft, so gehe ich dahin, wo am meisten See, am wenigsten Wiese ist, . . . also nach *Helgoland*.” (Here and throughout this essay, translations into English are my own unless otherwise indicated.)

<sup>2</sup> On nineteenth-century organizations see Allan Mitchell, “The Function and Malfunction of Mutual Aid Societies in Nineteenth-Century France,” in *Medicine and Charity before the Welfare State*, ed. Jonathan Barry and Colin Jones (London: Routledge, 1991), pp. 172–189; David G. Green, *Working-Class Patients and the Medical Establishment: Self-Help in Britain from the Mid-Nineteenth Century to 1948* (New York: Palgrave Macmillan, 1986); Martin Dinges, ed., *Medizinkritische Bewegungen im Deutschen Reich (ca. 1870–ca. 1933)* (Stuttgart: Steiner, 1996); Daniel Walther, *Medikale Kultur der homöopathischen Laienbewegung* (Stuttgart: Steiner, 2017); Michael Hau, *The Cult of Health and Beauty in Germany* (Chicago: Univ. Chicago Press, 2003); and Cornelia Regin, *Selbsthilfe und Gesundheitspolitik: Die Naturheilbewegung im Kaiserreich* (Stuttgart: Steiner, 1995). On developments in the 1960s see Alex Mold, *Making the Patient-Consumer: Patient Organisations and Health Consumerism in Britain* (Oxford: Oxford Univ. Press, 2015); and Thomasina Borkman, “A Selective Look at Self-Help Groups in the United States,” *Health and Social Care in the Community*, 1997, 5:357–364, <https://doi.org/10.1111/j.1365-2524.1997.tb00133.x>.

<sup>3</sup> Mold, *Making the Patient-Consumer*; Malcolm Nicolson and George Lewis, “The Early History of the Multiple Sclerosis Society of Great Britain and Northern Ireland: A Socio-Historical Study of Lay/Practitioner Interaction in the Context of a Medical Charity,” *Medical History*, 2002, 46:141–174, <https://doi.org/10.1017/S0025727300069064>; Nick Crossley, *Contesting Psychiatry: Social Movements in Mental Health* (Abingdon: Routledge, 2006); and Sandra Morgen, *Into Our Own Hands: The Women’s Health Movement in the United States, 1969–1990* (New Brunswick, N.J.: Rutgers Univ. Press, 2002).

<sup>4</sup> Maren Klawiter, *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism* (Minneapolis: Univ. Minnesota Press, 2008); and Peter-Paul Bänziger, “ExpertInnen statt AktivistInnen: Der Entpolitisierungsdiskurs in der Aids-Arbeit der 1980er Jahre,” in *Zeitgeschichte des Selbst*, ed. Pascal Eitler and Jens Elberfeld (Bielefeld: Transcript, 2015), pp. 261–277.

<sup>5</sup> Examples are the U.S. Hay Fever Association, founded in 1874 (see Gregg Mitman, “Hay Fever Holiday: Health, Leisure, and Place in Gilded-Age America,” *Bulletin of the History of Medicine*, 2003, 77:600–635); the German Diabetes Federation, founded in 1931 (see Sabine Roth, “Entwicklung und Aufgaben des Deutschen Diabetiker-Bundes” [Ph.D. diss., Heinrich-Heine-Universität, 1993]); and the Swedish Association for Heart and Lung Disease, founded in 1939 (see *Kartläggning av konsumentpolitiskt arbete i frivilliga organisationer* [Nordic Council of Ministers, 1993], p. 64).

must be asked what made the first patient organizations possible and what role they played in the medical field.

Organized groups of patients that engaged more actively in medical knowledge production, and thus challenged professional medical expertise, have thus far been documented from the 1980s onward. The foremost example is Steven Epstein's highly influential study of HIV/AIDS patients' participation in medical research; however, there are also other studies of patients that have taken the lead in this way. Michelle Murphy has shown how women office workers who shared and compared their embodied experiences contributed to assembling the concept of "sick building syndrome." Vololona Rabeharisoa and Michel Callon have shown how French muscular dystrophy patients accumulated knowledge, mobilized people and other resources, and built instruments to increase knowledge about an illness that, at the outset, was still unknown to many doctors.<sup>6</sup> Currently, this type of co-production of medical knowledge is growing exponentially.<sup>7</sup>

My approach to the topic differs from previous research both empirically and theoretically. Studying a patient organization from around the turn of the twentieth century offers a new way of contextualizing the patient movement and the role of patients in generating medical knowledge. The intention is not merely to show that the phenomenon is older than previously thought but to demonstrate that along with the periodization comes a different framework of medical reasoning against which the emergence of patient organizations can be better understood. Mutual influences between medical knowledge and organized patients reflected an epistemological shift around 1900, which was related to changes in disease models and modes of scientific observation.

It is generally held that Western science, including medicine, went through a process of increasing and then decreasing exclusivity of expertise during the nineteenth and twentieth centuries. The moment at which amateurs were largely pushed to the periphery of scientific practice, with the knowledge of medical professionals being separated from the common sense of ordinary people, arguably occurred sometime in the late nineteenth century.<sup>8</sup> Then, from the late twentieth century onward, lay participation in science appears to have experienced a revival—at first channeled through various social movements' demands for participation, then most recently through crowd-sourcing initiatives that let citizens engage in the co-production of knowledge.<sup>9</sup>

At the same time, the significance of scientific knowledge in everyday life increased, particularly in relation to the body. Many scholars have emphasized the role of knowledge—and not

<sup>6</sup> Steven Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge* (Berkeley: Univ. California Press, 1996); Michelle Murphy, *Sick Building Syndrome and the Problem of Uncertainty: Environmental Politics, Technoscience, and Women Workers* (Durham, N.C.: Duke Univ. Press, 2006); Vololona Rabeharisoa and Michel Callon, "Patients and Scientists in French Muscular Dystrophy Research," in *States of Knowledge: The Co-Production of Science and Social Order*, ed. Sheila Jasanoff (London: Routledge, 2004), pp. 142–160; and Rabeharisoa, "The Struggle against Neuromuscular Diseases in France and the Emergence of the 'Partnership Model' of Patient Organisation," *Social Science and Medicine*, 2003, 57:2127–2136, [https://doi.org/10.1016/s0277-9536\(03\)00084-4](https://doi.org/10.1016/s0277-9536(03)00084-4).

<sup>7</sup> Niccolò Tempini and David Teira, "Is the Genie Out of the Bottle? Digital Platforms and the Future of Clinical Trials," *Economy and Society*, 2019, 48:77–106, <https://doi.org/10.1080/03085147.2018.1547496>; Sara Riggare *et al.*, "Patients Are Doing It for Themselves: A Survey on Disease-Specific Knowledge Acquisition among People with Parkinson's Disease in Sweden," *Health Informatics Journal*, 2017, <https://doi.org/10.1177/1460458217704248>; and Paul Wicks, "Patient, Study Thyself," *BMC Medicine*, 2018, 16, art. 217, <https://doi.org/10.1186/s12916-018-1216-2>.

<sup>8</sup> Jeremy Vetter, "Introduction: Lay Participation in the History of Scientific Observation," *Science in Context*, 2011, 24:127–141, <https://doi.org/10.1017/S0269889711000032>; and Paul Starr, *The Social Transformation of American Medicine: The Rise of a Sovereign Profession and the Making of a Vast Industry* (New York: Basic, 1984). See also Ute Frevert, "Professional Medicine and the Working Classes in Imperial Germany," *Journal of Contemporary History*, 1985, 20:637–658.

<sup>9</sup> Bernadette Bensaude-Vincent, "A Historical Perspective on Science and Its 'Others,'" *Isis*, 2009, 100:359–368, <https://doi.org/10.1086/599547>.

least that of scientific knowledge—in fashioning modern subjectivities and interacting with the embodied experiences of ordinary people.<sup>10</sup> But the scientific knowledge employed in this way was, of course, in the words of Steven Shapin, also “produced by people with bodies, situated in time, space, culture, and society.”<sup>11</sup> In the case I will present, these subjectivities overlapped: the scientist-subject who generated knowledge and the general subject who incorporated knowledge in the construction of the self were one and the same person.

One of the many interrelated shifts in medical knowledge and practice between the late nineteenth and the early twentieth centuries was the emergence of disease specificity. Sickness had previously been understood as a state of derangement of the human system, occurring within an idiosyncratic body and bound to a particular environment. Modern medicine instead came to view diseases as specific entities that infiltrated the body—and hence released disease from its contingency on embodiment. Specific diseases were thus better suited to a science increasingly dominated by the demands of objectivity.<sup>12</sup> This “invisible revolution”—the ontological transformation of disease concepts into entities thought to exist independently of the individual, ailing person—generated and still carries a vast social power: it not only influences medical knowledge and practice but also contributes to the organization of clinics, the governance of health-care systems, and the management of populations. Other simultaneous transformations both contributed to and relied on disease specificity. Bacteriology offered empirical proof of disease entities that could be defined and studied outside of the body. New diagnostic tools and technologies reduced reliance on the patient’s reported feelings of distress.<sup>13</sup> Here, I am concerned with a further aspect of disease specificity: it made it possible for individuals to imagine themselves as one among many people “having” the “same” illness and thus provided an important foundation for the formation of patient organizations.

#### GATHERING AROUND HAY FEVER

First described in the early nineteenth century, hay fever was broadly defined as a curious seasonal sickness that appeared only in certain individuals. Its characteristics and name varied greatly, as did the theories regarding its cause: Was it a reaction to temperature or olfactory sensations, or was it simply a neurosis? From the 1870s onward, the character of the studies on this topic and the understanding of the phenomenon changed. Observations were systematized and increasingly focused on pollen and, later, on the immune system.<sup>14</sup> However, this

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<sup>10</sup> Nikolas Rose, *Governing the Soul: The Shaping of the Private Self* (London: Free Association, 1999); and Philipp Sarasin, *Reizbare Maschinen: Eine Geschichte des Körpers 1765–1914* (Frankfurt am Main: Suhrkamp, 2001). See also Jens Elberfeld, “Befreiung des Subjekts, Management des Selbst: Therapeutisierungsprozesse im deutschsprachigen Raum seit den 1960er Jahren,” in *Zeitgeschichte des Selbst*, ed. Eitler and Elberfeld (cit. n. 4), pp. 49–84; and Anne Waldschmidt, *Das Subjekt in der Humangenetik: Expertendiskurse zu Programmatik und Konzeption der genetischen Beratung 1945–1990* (Münster: Westfälisches Dampfboot, 1996).

<sup>11</sup> Steven Shapin, *Never Pure: Historical Studies of Science as If It Was Produced by People with Bodies, Situated in Time, Space, Culture, and Society, and Struggling for Credibility and Authority* (Baltimore: Johns Hopkins Univ. Press, 2010).

<sup>12</sup> Lorraine Daston and Peter Galison, *Objectivity* (Cambridge: Zone, 2007), pp. 27–39. On the early understanding of sickness see Conevery Bolton Valencius, *“The Health of the Country”: How American Settlers Understood Themselves and Their Land* (New York: Basic, 2002), pp. 71–74. For modern medicine’s view of disease see Michael Worboys, *Spreading Germs: Disease Theories and Medical Practice in Britain, 1865–1900* (Cambridge: Cambridge Univ. Press, 2000), pp. 278–286.

<sup>13</sup> Charles E. Rosenberg, “The Tyranny of Diagnosis: Specific Entities and Individual Experience,” *Milbank Quarterly*, 2002, 80:237–260.

<sup>14</sup> Hans Schadewaldt, *Geschichte der Allergie*, 4 vols., Vol. 1 (Munich: Dustri, 1980), pp. 5–38; Carla C. Keirns, “Germs, Vaccines, and the Rise of Allergy,” in *Crafting Immunity: Working Histories of Clinical Immunology*, ed. Jennifer Keelan, Kenton Kroker, and Pauline M. H. Mazumdar (Burlington, Vt.: Ashgate, 2008), pp. 77–103; and Mark Jackson, *Allergy: The History of a Modern Malady* (London: Reaktion, 2007), pp. 27–55.

did not mean that hay fever had entered the medical mainstream. At least until the 1920s, it was a fringe topic, studied most prominently by physicians who were sufferers themselves.

This gives a hint as to the particular sociocultural character of the disease: hay fever was one among several “maladies of civilization” that primarily plagued the affluent and educated classes who struggled to keep up with the strains of modernity. Many of these urban, educated, well-off people were physicians. Conveniently enough, the typical sufferers were also the kind of people who could afford the therapy of choice, a “hay fever holiday” in the pollen-free air of a mountain or seaside resort.<sup>15</sup>

Hay fever hence had a mobilizing power that pushed people who shared certain social characteristics toward particular places at specific times, thus providing one basic prerequisite for a patient group to form. One of those places was the North Sea island of Heligoland. With an area of just half a square mile, its combined features made it an ideal place to escape the early summer pollen season. It is located far—29 miles—from the mainland and, until 1947, consisted of a vegetated “upper land” separated from the sandy “lower land” by a cliff wall 200 feet high.<sup>16</sup> Mainland pollen did not reach as far as the island, and only under exceptionally unfortunate weather conditions would the blossoming grass of the upper land bother those dwelling on the lower land. Tourism to Heligoland began in the 1820s; thus, in the early days of the Heufieberbund, the facilities there were well established and tailored to a clientele of the more glamorous sort: artists, poets, aristocrats, and wealthy members of the bourgeoisie.<sup>17</sup>

Sometime after Schultz had begun spending each spring on Heligoland, he heard about a disease called hay fever and concluded that this was what he was suffering from. In collaboration with the bath directorate—the local public office that ran the bathing facilities—he placed advertisements in mainland newspapers that advised others with the same disease to follow his example. After two seasons of advertising, a small group of ten hay fever sufferers assembled on the island and formed the Heufieberbund.<sup>18</sup>

Through the character of the members’ illness, and the chosen center for their activities, the Heufieberbund of Heligoland carried a twofold mark of social distinction. It did not represent merely sick people, but people of a certain class and lifestyle, with the financial means and education to give them confidence enough to engage in discourse on equal footing with any medical professional.

Soon the Heufieberbund unfolded an ambitious program to promote acceptance of and knowledge about the diagnosis by issuing and circulating an annual report. From 1899 up to 1972, the organization published seventy such reports, which together comprise a corpus of nearly eight thousand pages. However, most of the contents were not, as one might expect from an annual report, about the organization. Instead, these publications were primarily about the disease itself: the reports contained substantial amounts of original research about its symptoms, epidemiology, etiology, and therapy.

### OBSERVING HAY FEVER

Hay fever was not a clearly defined object, either colloquially or scientifically, when the Heufieberbund formed. This was not only because there was disagreement as to the name

<sup>15</sup> Mitman, “Hay Fever Holiday” (cit. n. 5).

<sup>16</sup> In 1947 the British Royal Navy executed the “big bang,” a gigantic controlled detonation to demolish the military fortifications on the island, permanently altering its shape. See Jan Rüter, *Heligoland: Deutschland, England und ein Felsen in der Nordsee*, trans. Karl Heinz Siber (Berlin: Propyläen, 2018), pp. 331–334.

<sup>17</sup> *Ibid.*, pp. 75–79, 161–167.

<sup>18</sup> Albrecht et al., *Bericht X des Heufieberbundes von Helgoland nach den Mitteilungen von Heufieberkranken und nach wissenschaftlichen Schriften* (cit. n. 1), p. 57.

and etiology of the disease; the uncertainty went much deeper. There was significant doubt about whether hay fever was a distinct illness at all—and, if it was, the symptoms were so vague, so variable, and so highly subjective that it was extremely unclear where its outline was to be drawn. The first task of the Heufieberbund was therefore to contribute to the crystallization of the illness itself and its characteristics. From Lorraine Daston's work, we know that this type of mission makes up the core of scientific observation. Expert observers, she argues, have trained their perception to distinguish distinct, knowable objects in the world and thus organize it and make it intelligible.<sup>19</sup>

The Heufieberbund wanted to establish the disease as a knowable object for several reasons. They wanted it to be acknowledged as a particular type of object, a somatic illness, and they wanted to defend it against claims that it was a different type of object—namely, a fashion or a neurosis. Furthermore, they wanted to be cured, and they believed that the key to relief was medical knowledge. In order for medicine to find a cure, there needed to be a reasonably distinct disease object to provide a cure for; hence, they directed their efforts toward stabilizing hay fever and making it a knowable object. They had a very important resource at hand for doing so: their own bodies, which contained the object they wanted to define.

The first Heufieberbund report was fairly modest, consisting of seven pages handwritten by Schultz and distributed, apparently in at least two “editions,” in 1899. In this report, he advised sufferers of hay fever—which he described as an increasingly common illness with no known cure—to avoid blossoming crops, grass, and trees by traveling to a suitable place.<sup>20</sup> In the years that followed, other authors joined Schultz in producing the reports, which were now printed booklets containing yearly revised and amended reviews of the available knowledge about hay fever. The volume fluctuated from year to year: in 1901 the report had thirty-two pages, in 1902 it had seven pages, and in 1904 it had 110 pages. All Heufieberbund members received the report, as did many nonaffiliated hay fever sufferers whose addresses the organization had gained access to, along with selected doctors, clinics, and universities.<sup>21</sup>

The early reports carried the subtitle “Based on Reports from Hay Fever Sufferers and Scientific Publications” (or variations on that theme), which gives a good indication of how they were produced.<sup>22</sup> They presented an essayistic “conversation” between various individual experiences of suffering from hay fever, state-of-the-art medical research, and miscellaneous news and notes. Behind these texts was a particular strategy: when they assembled at Heligoland, the Heufieberbund members discussed the disease and traded experiences and advice. Schultz and his companions documented and systematized what was said in these discussions and used them as source material for the annual reports.<sup>23</sup>

At the outset, then, personal experiences of suffering and relief recounted by a small group of people seeking refuge at a seaside resort were some of the chief sources of credible information about hay fever. Soon the discussion expanded beyond the personal encounters at Heligoland. People would write to the Heufieberbund board to ask for their opinions and advice or to share their experiences and coping strategies. The correspondence contained information about

<sup>19</sup> Lorraine Daston, “On Scientific Observation,” *Isis*, 2008, 99:97–110, <https://doi.org/10.1086/587535>.

<sup>20</sup> See Otto Schultz, “Das Heufieber: Bericht I des Heufieberbundes von Helgoland” (facsimile), in Heufieberbund von Helgoland, *Bericht 40 über das Jahr 1937* (Verein zur Bekämpfung des Heufieberleidens, 1938), pp. 1–8.

<sup>21</sup> Heufieberbund von Helgoland, “An unsere Heufieber-Leidensgefährten!” 1906, Bayerische Staatsbibliothek, Munich, 4 Path. 150 g-1901/09.

<sup>22</sup> “Nach den Mitteilungen von Heufieberkranken und nach wissenschaftlichen Schriften.”

<sup>23</sup> Richard Mohr and Richard Baerwald, *Das Heufieber, seine Linderung und seine Behandlung: Bericht III auf Grund der vom Heufieberbund von Helgoland bei Heukranken und Ärzten veranstalteten Umfragen* (Heufieberbund von Helgoland, 1901), p. 3.

how the illness manifested in a greater number of people, and this data found its way into the reports just as the direct communications at Heufieberbund get-togethers had.

Aiding this work was a questionnaire, which was introduced in 1901 in an attempt to have the members report their experiences in a form that was easier to evaluate. An editorial team then sifted through letters and questionnaire responses, picked out information that was thought to be valuable to other sufferers, and presented it in a systematic way, together with news from the research front and their own personal experiences. With this new method, the Heufieberbund formed a “field network”: a grid of lay observers that reported their findings back to a central hub.<sup>24</sup> In this case, the central hub was the board and the editors of the reports. Otto Schultz was part of the editorial team each year until he left the organization in 1914. The other editors of the first fifteen reports included the psychologist Richard Baerwald, the physicians Richard Mohr, Ernst Schneider, and Theodor Albrecht, and the chemist Gotthold Fuchs. All of them were members of the Heufieberbund and suffered from hay fever.

A wide variety and an increasing volume of information and experience were available to the editors of the early Heufieberbund reports. Each editor had his own embodied experience of what it was like to suffer from hay fever. From the accounts of others—questionnaire responses, letters, and face-to-face exchanges on Heligoland—he also had access to a great number of other embodied experiences of the disease. Furthermore, there were published descriptions and studies from the medical literature, in which physicians described the illness in patients they had met and examined. Taken together, this was a vast and chaotic mass of various types of information: about watering eyes, sneezing, and headaches; about the effects of warm weather, rain, and wind; and about the use of vaporizers, silk veils, and cocaine.

Organizing this flow of information in a way that reflected the characteristics of the disease was a painstaking process. According to Richard Mohr, who coedited five of the reports, his work consisted of “the separation of the important from the less important or already known.”<sup>25</sup> Mohr described the process that went into the 1904 report as follows: Schultz performed the initial “inspection and classification,” and he himself carried out the “processing” of over a thousand items, including “hundreds of letters containing more or less elaborate reports and remarks by the hay fever sufferers on their illness.”<sup>26</sup> In addition, Mohr had at his disposal 186 completed questionnaires and letters that he considered systematic and comprehensive enough to be translatable into quantitative data. Over the subsequent hundred pages of the report, he structured the information provided by the Heufieberbund members, moving from the general characteristics of hay fever patients—their sex, age, and location—to treatment options categorized as internal remedies, external remedies, surgical treatments, protective apparatuses, and natural remedies. Next came a chapter on “miscellaneous” treatments (such as hypnosis) and a section on health resorts. The report closed with a list of “General Rules and Advice” regarding

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<sup>24</sup> For the introduction of the questionnaire see Heufieberbund von Heligoland, “An unsere Heufieber-Leidensgefährten,” Dec. 1901, Bayerische Staatsbibliothek, 4 Path. 150 g-1901/09. On field networks see Jeremy Vetter, “Lay Observers, Telegraph Lines, and Kansas Weather: The Field Network as a Mode of Knowledge Production,” *Sci. Context*, 2011, 24:259–280, <https://doi.org/10.1017/S0269889711000093>.

<sup>25</sup> Richard Mohr, *Das Heufieber, sein Wesen und seine Behandlung: Bericht VI auf Grund der vom Heufieberbund von Heligoland bei Heukranken und Ärzten veransalteten Umfragen sowie auch der neueren wissenschaftlichen Veröffentlichungen* (Heufieberbund von Heligoland, 1904), p. 3: “der Scheidung des Wesentlichen von mancherlei weniger Wichtigem oder doch schon längst Bekanntem.”

<sup>26</sup> *Ibid.*, p. 3: “Sichtung und Anordnung”; “Verarbeitung”; “hunderte von Briefen mit mehr oder minder ausführlichen Berichten oder Bemerkungen der Heufieberkranken über ihr Leiden.”

personal hygiene, diet, and conduct during the pollen season—for example, how to wash used handkerchiefs, when and how to take walks, and how to groom one's beard.<sup>27</sup>

In each of the sections, Mohr presented data from the letters and questionnaires in the form of both numbers and individual narratives, comparing what he had gleaned from the membership with results from medical literature and statements of what he considered to be common knowledge. There were, we learn, 132 men and 54 women among the questionnaire respondents. However, Mohr pointed out that this should not be taken as proof of the relative occurrence of hay fever in the sexes, since it deviated considerably from a study published in the medical journal *Münchener Medizinischen Wochenschrift* in the previous year. Those results, in turn, matched more closely the representation of men and women among Heufieberbund members, leading Mohr to conclude that a ratio of 1.7–1.75 men per woman was more accurate. Further on, he reported that only about half of the respondents suffered from asthma and concluded that this made the call from a Dutch physician to rename the condition “pollen asthma” unsuitable. He then reported that of those who suffered from asthma, most agreed that it usually came on two to three weeks after the hay fever season had begun, which, as Mohr emphasized, corresponded with the findings of a French study from 1899. Also, most respondents stated that the asthma was worse during the night—“although *one* is asserting the exact opposite.”<sup>28</sup>

Mohr carried on in this way, letting the questionnaires and letters speak to the medical literature, mutually validating or questioning each other, throughout the report. He also continued conscientiously to account for singular experiences. One patient, he reported, had good results with atropine, another found it helpful only sometimes, and a third was noted to have “no results worth mentioning.”<sup>29</sup> Mohr not only treated remedies this way but also incorporated other types of useful practices, such as one patient who reported that he would clear his nose by blocking the nostrils with his knuckles and puffing up his nose with air. In addition, Mohr repeatedly noted his own symptoms and compared them with findings in the medical literature and reports from other members.<sup>30</sup>

By treating notes and data from physicians and patients equally, and making no distinction between his professional medical viewpoint and his lived experience as a hay fever sufferer, Mohr made the voice of the physician indistinguishable from that of the patient. He not only attempted to determine trends and tendencies in the material at hand but also acknowledged isolated and contradictory cases. The result was a presentation that conveyed that subjective experience within an individual body afflicted with hay fever was indispensable—the disease could not be reduced to averages. As Mohr phrased it, “Every patient is different, and the hay fever patient especially so.”<sup>31</sup> Therefore, he urged the members to use their best judgment and seek out the treatments that worked for them. Although being able to make generalizations is one of the main benefits of assembling and maintaining a field network, the Heufieberbund was reluctant to make full use of that feature.<sup>32</sup> Perhaps this was due to the relatively nonhierarchical structure, in which each participant, whether observer or editor, was a member of the same organization and suffered from the same disease. Even though the editors were often medical professionals, they were also Heufieberbund members and patients themselves. Hence the difference in status between the editors and the other members, who were also mostly well off and educated, was not

<sup>27</sup> *Ibid.*, pp. 96–104.

<sup>28</sup> *Ibid.*, pp. 6–7 (discussion of proportion of men and women), 39: “freilich behauptet *einer* wider genau das Gegenteil.”

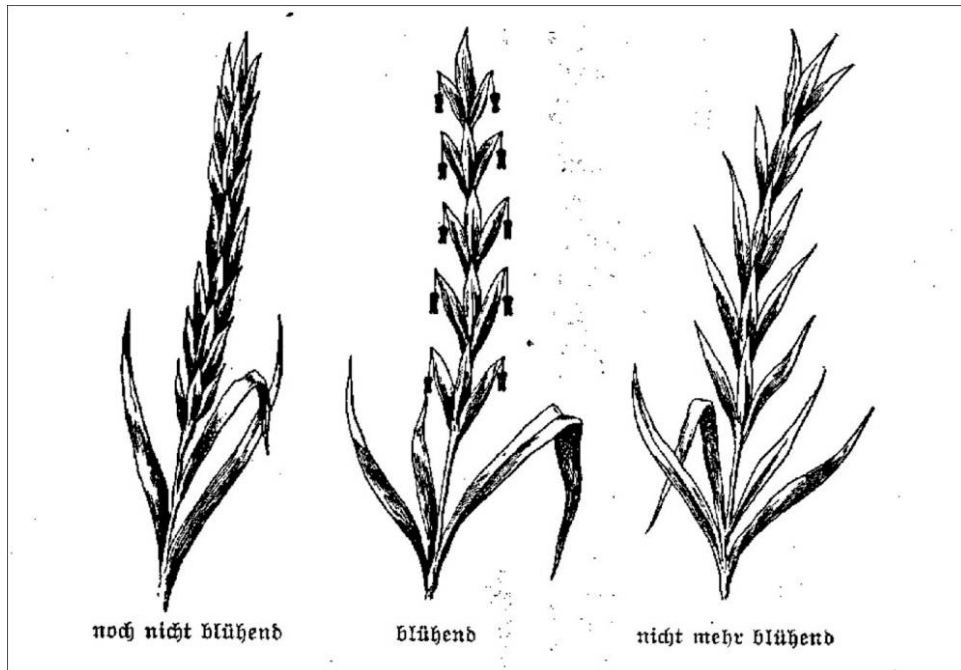
<sup>29</sup> *Ibid.*, p. 58: “keinen nennenswerten Erfolg.”

<sup>30</sup> *Ibid.*, pp. 79, 35–36, 40.

<sup>31</sup> *Ibid.*, p. 47: “Die Patienten sind verschieden geartet und die Heufieberpatienten erst recht.”

<sup>32</sup> *Ibid.*, pp. 102–103 (using best judgment). On the benefits of field networks see Vetter, “Lay Observers, Telegraph Lines, and Kansas Weather” (cit. n. 24).





**Figure 1.** Illustration of the different stages of grass blossom. From *Bericht IX des Heufieberbundes von Helgoland nach den Mitteilungen von Heufieberkranken und nach Wissenschaftlichen Schriften* (Heufieberbund von Helgoland, 1907), p. 44.

particularly large and offered no mandate to erase individual, divergent experiences by means of generalization.

The emphasis on the individual, subjective experience and on each sufferer finding a suitable remedy for himself or herself did not mean that data collection and self-observation were unstructured. On the contrary, the Heufieberbund officials made efforts to train and instruct the members in how and what to observe. Not only did they provide a list of questions; they also gave additional guidance in how to make the necessary judgments and, at times, asked for special attention to particular aspects of the disease. When noting the effect of a drug, the members were asked to document the exact circumstances of the intake: whether it occurred at the beginning or at the height of the symptoms, what the weather had been like, and whether the drug provided relief only indoors or outside as well.<sup>33</sup> Drawings of grass in different stages of blossom equipped readers to determine the risk of an attack more accurately and, therefore, to judge whether the absence of symptoms was due to a particular medicine or just to the fact that no pollen was present (see Figure 1).<sup>34</sup>

On other occasions, the members were called on to verify a new finding in the medical literature. In 1904 Mohr asked the readers to pay particular attention to their eye and knee reflexes: “This is because Dr. Alberts has observed *different width and slow reaction of the pupils*,

<sup>33</sup> Theodor Albrecht and Otto Schultz, *Bericht XII nach den Mitteilungen von Heufieberkranken und nach wissenschaftlichen Schriften* (Heufieberbund von Helgoland, 1910), p. 4; and Albrecht and Schultz, *Bericht XI nach den Mitteilungen von Heufieberkranken und nach wissenschaftlichen Schriften* (Heufieberbund von Helgoland, 1909), p. 4.

<sup>34</sup> Otto Schultz, “Luftkurorte,” in *Bericht IX des Heufieberbundes von Helgoland nach den Mitteilungen von Heufieberkranken und nach wissenschaftlichen Schriften* (Heufieberbund von Helgoland, 1907), pp. 43–44.

and increased patellar (kneecap) tendon reflex in some hay fever cases. It would be important to us to receive confirmation of this finding from a different source.”<sup>35</sup> The “different source” that would validate the professional judgment of the cited medical expert was the self-observation of symptoms in the sufferers’ own bodies; yet it was a type of self-observation that was more sophisticated than merely reporting a feeling of distress. The same is true for the pleas to note the time and circumstances of suffering and relief: the lay observers were encouraged to cultivate their observational practices.

It is not unlikely that the editors had elsewhere encountered books that trained the observational skills of laypeople. For instance, botanical books aimed at amateurs and the general public were a widespread genre in the nineteenth century and well into the twentieth century.<sup>36</sup> Lay botanists learned from these books how to identify and preserve plants and how to order them according to scientific standards; in a similar way, the Heufieberbund members learned how to identify, categorize, and describe the symptoms of their illness.

Scientific observation is a type of particularly refined experience, developed out of more commonplace modes of sensing and perceiving.<sup>37</sup> Through the Heufieberbund reports, a reverse process took place in which ordinary and very personal experience developed out of scientific modes of observation. Compared with other field guides for amateur observers, these reports contributed to training and cultivating the observational habits of the Heufieberbund members in a more intimate way: amended yearly, the catalogue of hay fever symptoms guided the reader in how to read his or her own body. A particular truth could be generated from subjective experience if the subject was trained to use the right techniques for observing and recording it. Systematic self-observation by the afflicted, using techniques derived from scientific observation, was a way of testing the results that medical science generated about the disease, to see if they held up.

Hay fever manifested itself through a wide array of discomforts that affected different parts of the body: sneezing, runny eyes, headaches, asthma, poor sleep, nervousness, fatigue, sensitivity to light, and many others. Further complicating the matter, the specific combination of symptoms could vary greatly between sufferers, over time, and depending on climate and place. A description of all the vague and ephemeral pains and discomforts experienced by other hay fever sufferers brought order to chaotic sensations by naming and categorizing them, which facilitated the interpretation of one’s own body and turned the experience of discomfort into a mode of observation. In the words of Otto Schultz, the hay fever season was a “time of suffering and learning,” when those afflicted with hay fever gathered “experiences in the field of hay fever therapy.”<sup>38</sup>

Hay fever sufferers organized in the Heufieberbund to pursue a shared goal: to generate a stable kind—hay fever—out of the chaotic sensations within their bodies. They did not rely solely on their own bodily sensations; they were eager to absorb knowledge from professional physicians and scientists and to blend that knowledge with their own embodied experience. In this way, the Heufieberbund not only helped to establish a disease category but simultaneously

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<sup>35</sup> Mohr, *Das Heufieber, sein Wesen und seine Behandlung* (cit. n. 25), p. 41: “Dr. Alberts hat nämlich . . . in einigen Fällen bei Heufieberkranken auch verschiedene Weite der Pupillen, träge Reaktion derselben . . . , und Verstärkung der Patellar- (Knie-scheiben-) Sehnenreflex beobachtet. Es wäre für uns wichtig, diese Wahrnehmung auch von anderer Seite bestätigt zu finden.”

<sup>36</sup> Jenny Beckman, “Collecting Standards: Teaching Botanical Skills in Sweden, 1850–1950,” *Sci. Context*, 2011, 24:239–258, <https://doi.org/10.1017/S0269889711000081>; and Anne Secord, “Pressed into Service: Specimens, Space, and Seeing in Botanical Practice,” in *Geographies of Nineteenth-Century Science*, ed. David N. Livingstone and Charles W. J. Withers (Chicago: Univ. Chicago Press, 2011), pp. 283–310.

<sup>37</sup> Lorraine Daston and Elizabeth Lunbeck, *Histories of Scientific Observation* (Chicago: Univ. Chicago Press, 2011), p. 3.

<sup>38</sup> Otto Schultz and Theodor Albrecht, *Bericht XIV des Heufieberbundes von Helgoland nach den Mitteilungen von Heufieberkranken und nach wissenschaftlichen Schriften* (Heufieberbund von Helgoland, 1912), pp. 8–9: “Leidens- und Erfahrungszeit”; “auf dem Gebiet der Heufieberbehandlung gemachten Erfahrungen.”

generated a distinct mode of relating to oneself. Cultivated habits not only aided observation for the sake of establishing a knowable object; they also directed the reading of one's own body. More specifically, the habits of perception that the Heufieberbund taught its members consisted of reading the body through a medical lens. The cultivation that they underwent when they learned to categorize, measure, and document their suffering was a medical one. They were taught to see the common world, their mundane and chaotic sense of distress and discomfort, expertly as expressions of illness.

#### ILLNESS EXPERIENCE AND KNOWLEDGE ABOUT DISEASE

The authors of the early Heufieberbund reports were convinced that the embodied illness experience was a central asset in producing knowledge about their shared disease, and they were not alone in this belief. In the summer of 1907, the daily newspaper *Neue Hamburger Zeitung* reported from the “hay fever colony” at Heligoland in a front-page article. The author presented the Heufieberbund as a trailblazing institution in the medical sphere. He argued that the organization, through its ability to mobilize patients to observe their illness and the treatments they underwent, could generate more accurate data than specialized physicians. Already, according to the article, the organization had produced substantial knowledge about the disease:

We see here for the first time an organization of the sick, who have joined together in order to fight a shared, unknown and unexplored disease. This process should serve as a model for other illnesses. The results that the Heufieberbund has produced during its eight years of activity are astonishing. A physician, even a specialist, could never have gathered such material. What a physician can observe is above all the clinical picture of an illness. He quickly loses sight of the patient and can only in the rarest of cases track the therapeutic results. The Heufieberbund, which also has physicians afflicted with hay fever on its administrative board, possesses the statements of nearly a thousand people who are afflicted with hay fever.<sup>39</sup>

This article presented the Heufieberbund to the general public as an exceptionally credible source of medical knowledge because it was in possession of the accumulated, colloquial, subjective experiences of a large number of hay fever sufferers. A physician, on the other hand, not only had a much smaller number of patients but only saw them in the medical setting, with little access to the real, lived experience of being sick.

It is important to note that neither this article nor the Heufieberbund publications presented the organization's activities as being in opposition to medicine. The expertise of trained physicians was not rejected. Rather, it was sought after and emphasized: physicians were commissioned to produce the annual reports, and indeed—as the news article remarked—physicians

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<sup>39</sup> J. v. K., “Heuschnupfer-Salon Auf Helgoland,” *Neue Hamburger Zeitung*, 24 June 1907: “Wir sehen hier zum ersten Mal eine Vereinigung von Kranken, die sich zusammengetan haben, um gegen ein gemeinsames, unbekanntes und unerforschtes Leiden zu kämpfen. Dieses Verfahren müßte vorbildlich für andere Krankheiten werden. Die Resultate, die der Heufieberbund im Laufe seiner achtjährigen Tätigkeit erzielt hat, sind staunenswert. Nie hätte ein Arzt, sogar als Spezialist, ein solches Material zusammengebracht. Was ein Arzt beobachten kann, ist vornehmlich das klinische Bild einer Krankheit. Er verliert aber alsbald seinen Patienten aus den Augen und kann nur in den seltensten Fällen die Resultate der Kur verfolgen. Der Heufieberbund, zu dessen Vorstandsmitgliedern auch heufieberkranke Ärzte zählen, verfügt über die Aussagen von nahezu tausend Heufieberkranken.” It is possible that this article is one of the free texts that the Heufieberbund provided to newspapers as part of its self-marketing. However, no one with the initials J. v. K. appears in the member directory. See Heufieberbund von Helgoland, “Verzeichnis der ordentlichen Mitglieder,” 1907, Bayerische Staatsbibliothek, Path. 1316 i-1901/12; see also Albrecht *et al.*, *Bericht X des Heufieberbundes von Helgoland nach den Mitteilungen von Heufieberkranken und nach wissenschaftlichen Schriften* (cit. n. 1), p. 58.

were members of the association. Initially, however, professional medicine played a remarkably small role in the way in which the Heufieberbund discussed the illness. As the engagement of medical professionals in researching and treating the disease grew, conflicts about objectivity and truth surfaced.

In the very first Heufieberbund report from 1899, Schultz had advised his fellow sufferers that flushing the eyes and nose with water was a better remedy than any available medicine. He noted, however, that the only truly effective way to fight the disease was to avoid blossoming crops, grass, and trees.<sup>40</sup> When the patient organization first formed, hay fever was more a matter of climate, botany, and travel than of medicine. In the third annual report, only eight out of thirty-two pages were devoted to specific medical treatments; the rest focused on describing the symptoms, listing suitable resorts, presenting methods for shielding oneself from pollen exposure, and giving lifestyle advice.<sup>41</sup> However, one of the Heufieberbund's objectives in generating knowledge about hay fever was to raise interest in the disease among members of the medical profession. For this purpose, Schultz and the secretary and physician Ernst Schneider attended the annual conference of the Society of German Natural Scientists and Physicians in 1901. Schneider took this opportunity to present the organization and outline its scope to his medical colleagues, assuring them that there was no resentment—on the contrary, he promised, “the association endeavors to cooperate with all efforts in the spreading of knowledge of the disease among general practitioners and in scientific research.”<sup>42</sup>

Clearly, there were concerns at this point within the medical profession about the purpose of the patient organization, especially with regard to whether it would seek to undermine or challenge medical expertise and whether it should be taken seriously. In the following year Julius Rudolph, a gynecologist from Heilbronn, published a lengthy article in Germany's leading psychiatric journal arguing that hay fever was a neurosis. His foremost evidence was the very existence of the Heufieberbund, which he described as an expression of a “hysterical desire to appear interesting.”<sup>43</sup> Schultz and Schneider's conference attendance, and the increasing attention they and their fellow editors paid to medical perspectives on hay fever in the following years, were attempts to win over the medical community and build an alliance with it. The physicians on the board and among the editors—Schneider, Mohr, and Albrecht—were important figures in this process. They could speak with the twofold credibility of professional expertise and lived experience and could mediate between the two.

Schneider had brought up one important criticism in his address at the medical conference: hay fever patients were dissatisfied with the available medical options. They did not reject medical expertise, but they were frustrated that it still had no solution to offer them. In 1903, however, William Phillipps Dunbar published groundbreaking results from his research on hay fever in a small book. Dunbar was an American physician and the director of the State Hygienic Institute in Hamburg. Like many others in the field, he suffered from hay fever himself and was a proponent of the still-contested theory that pollen was the causative agent. Specifically, he believed that pollen contained a toxin that only certain people were sensitive to. As Carla C. Keirns has shown, Dunbar did not think of hay fever precisely as an immunological pathology

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<sup>40</sup> Schultz, “Das Heufieber” (cit. n. 20).

<sup>41</sup> Mohr and Baerwald, *Das Heufieber, seine Linderung und seine Behandlung* (cit. n. 23), pp. 20–27.

<sup>42</sup> Otto Schultz and Ernst Schneider, *Vierter Bericht über die Thätigkeit und die Erfahrungen des Heufieberbundes von Helgoland* (Heufieberbund von Helgoland, 1902), p. 4: “der Bund ist bestrebt, bei der Ausbreitung der Kenntniß der Krankheit unter den praktischen Aerzten und bei der wissenschaftlichen Erforschung derselben mit allen Kräften mitzuwirken.”

<sup>43</sup> Julius Rudolph, “Das Heufieber vom Standpunkt der Psychiatric,” *Allgemeine Zeitschrift für Psychiatric und Psychisch-Gerichtliche Medizin*, 1902, 59:912–940, on p. 913: “hysterisches Interessanterscheinenwollens.”

but, rather, saw it as a type of poisoning. In his view, the pollen toxin itself caused the illness, but most people were immune to it. The therapy he suggested was passive immunization: after injecting animals with the pollen toxin, he extracted from them a serum containing antibodies.<sup>44</sup>

Dunbar's book resembled the Heufieberbund reports in many ways. Like his fellow sufferers in the patient organization, he mixed original research with personal experience, communications with a variety of acquaintances, and a review of previous research. He had himself suffered from hay fever since 1895 and, much as the Heufieberbund members were encouraged to do, he had since then made systematic observations of the way the illness manifested in his body. The patterns he was thus able to detect led him to believe that pollen was the culprit. In his "preliminary trials," as he called them, Dunbar used his own body and the windows and vents of train cars, offices, and living rooms. He noticed how his symptoms set in when traveling by train through cultivated fields but ceased when the train entered a forest. If he closed the windows of his compartment he stopped sneezing, despite the bright sunshine and fields outside. Guided by these findings, he was successful in avoiding all hay fever attacks by keeping the windows closed at home as well as at the office throughout the critical season.<sup>45</sup>

To Dunbar, these findings were of great interest, as they supported the pollen hypothesis; nevertheless, in order to prove it he required a different method. First, he collected and isolated pollen from different plants. He then used a cotton swab to insert pollen into the eyes and noses of three known sufferers of hay fever and three controls. The afflicted persons had immediate and visible reactions: their eyes and noses became swollen and watery, and they sneezed profusely. These were the "objective" signs, according to Dunbar; there were also several "subjective" symptoms: pain, tiredness, itchiness, and "a feeling of general discomfort."<sup>46</sup> In a further experiment, he placed a hay fever patient and a gentleman unafflicted by hay fever together in a glass box, each holding a dish filled with pollen. By blowing air onto the dishes, they distributed the pollen in the sealed-off environment of the glass box. After four minutes, the hay fever patient reported a pain in the chest and began to cough, while the control was completely unaffected. As they exited the box, the hay fever patient reported that he felt weak and out of breath, and, "objectively, there was verifiable inspiratory stridor."<sup>47</sup> Again, Dunbar did not disregard subjective experience. It was one of the clinical signs of hay fever, besides visibly swollen eyes and audibly obstructed breath. But the subjective experience was not a type of observation. It was filtered through the judgment of Dunbar's scientific self, using techniques and tools of objectivity: controls, glass boxes, protocols.

Dunbar had developed these techniques to prove that hay fever was a reaction to pollen toxin, and he used them again in the next step of his investigation, which was to develop and test an antitoxin. In the same year that he published his research, he brought a serum-based medicine to the market under the name Pollantin—the first specific hay fever medicine to come out of a medical research laboratory. Dunbar's results caused overwhelming enthusiasm in the Heufieberbund. Although they had just sent out the report for 1903, they decided not to wait for the next spring but to print a second edition to let all the members know about this new, groundbreaking discovery. Richard Mohr was the main author of this report, and he especially emphasized the fact that not only were "laboratory studies on artificially 'infected' hay-sick persons" now available, but also reports from "people who are momentarily suffering

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<sup>44</sup> William Phillipps Dunbar, *Zur Ursache und spezifischen Heilung des Heufiebers* (Munich: Oldenbourg, 1903); and Keirns, "Germs, Vaccines, and the Rise of Allergy" (cit. n. 14).

<sup>45</sup> Dunbar, *Zur Ursache und spezifischen Heilung des Heufiebers*, pp. 10–13.

<sup>46</sup> *Ibid.*, pp. 15–16: "ein Gefühl allgemeinen Unbehagens."

<sup>47</sup> *Ibid.*, p. 20: "objektiv war inspiratorischer Stridor nachweisbar."

from genuine, naturally induced hay fever.<sup>48</sup> Mohr cited one such statement, allegedly a letter from a satisfied patient to Dunbar, and commented on it with an immensely optimistic attitude: “Professor Dunbar has *actually succeeded* in producing an *effective antitoxin*, that is a *specific cure* from the blood serum of rabbits inoculated with pollen toxin.”<sup>49</sup> He also noted the address of the supplier. Now, Mohr instructed the members in his preface, it was up to them: after this year’s pollen season, they should communicate their results back to him, and then “the next annual report will hopefully have a great deal of pleasing news to disclose.”<sup>50</sup>

But what the members subsequently reported was not as pleasing as Mohr had expected: only about half of those who tried Pollantin noted beneficial results. Statistically speaking, a 50 percent success rate for the treatment might appear to be a decent outcome, but the enthusiasm had noticeably waned. In the context of the Heufieberbund reports, the prime focus was not averages but subjective experience. What the reports conveyed, along with a number of successes, was that many people had tried Pollantin but had not experienced any relief or indeed had adverse reactions.<sup>51</sup> From the subjective standpoint of those individuals, Pollantin did not work at all, and this perspective was an important one. Hay fever as an object was still deeply entrenched in the subjective world of individual, embodied experience; it was not yet fully an objectified disease.

Initially, Mohr held on to the hope that Pollantin might still be the answer all hay fever patients yearned for. While reporting disappointing results, he reminded the members to follow the instructions precisely, as perhaps misapplication was to blame for some negative outcomes.<sup>52</sup> When the vice president and pharmacist Gotthold Fuchs took over the pharmaceutical section of the report in 1906, he presented more overt criticism. There was, noted Fuchs, a significant discrepancy between Dunbar’s statistics and those of the Heufieberbund. Dunbar’s numbers made Pollantin seem significantly more effective than the members’ reports indicated. Besides, Fuchs remarked in the following year, what about the adverse reactions? Angrily, he commented that the professor was silent on that matter, “although Dunbar observed conjunctivitis and severe redness of the entire eyeball as a result of his Pollantin powder on myself in 1903.”<sup>53</sup>

At this moment, Dunbar was facing criticism and competition from other sources as well. One of his assistants launched a competing pollen serum, and reports of anaphylactic reactions to Pollantin accumulated in the professional medical press. Nevertheless, the criticisms from the Heufieberbund in particular bothered him enough that he addressed them in a speech at the Berlin Congress of the Royal Institute of Public Health, published in the *Journal of Hygiene* in 1913: “My favorable results were in direct opposition to those of the German Hay-Fever Association. My endeavor to defend myself against such attacks led me to place my material at

<sup>48</sup> Richard Mohr, *Fünfter Bericht über die Tätigkeit und die Erfahrungen des Heufieber-Bundes von Helgoland*, 2nd ed. (Heufieberbund von Helgoland, 1903), p. 3: “im Laboratorium und an künstlich ‘infizierten’ Heukranken”; “solchen Personen, die zur Zeit am echten, auf natürlichem Wege entstandenen Heufieber leiden.”

<sup>49</sup> *Ibid.*, p. 18: “es Herrn Professor Dunbar *wirklich gelungen* ist, aus dem Blutserum mit Pollengift geimpfter Kaninchen ein *wirksames Gegengift*, also ein *spezifisches Heilmittel* herzustellen.”

<sup>50</sup> *Ibid.*, p. 4: “Der nächste Bundesbericht wird darüber hoffentlich recht viel Erfreuliches mitzuteilen wissen.”

<sup>51</sup> Mohr, *Das Heufieber, sein Wesen und seine Behandlung* (cit. n. 25), pp. 42–43; and Richard Mohr, *Neues vom Heufieber: Bericht VII auf Grund der vom Heufieberbund von Helgoland bei Heukranken und Ärzten veransalteten Umfragen sowie auch der neueren Wissenschaftlichen Veröffentlichungen* (Heufieberbund von Helgoland, 1905), p. 62.

<sup>52</sup> Mohr, *Das Heufieber, sein Wesen und seine Behandlung*, p. 43.

<sup>53</sup> Gotthold Fuchs, “Die Mittel zur Bekämpfung bzw. Linderung des Heufiebers,” in *Bericht VIII des Heufieberbundes von Helgoland nach den Mitteilungen von Heufieberkranken und nach wissenschaftlichen Schriften* (Heufieberbund von Helgoland, 1906), pp. 22–36, on p. 29; and Fuchs, “Kurze Bemerkungen über die Heuschnupfen-Linderungsmittel,” in *Bericht IX des Heufieberbundes von Helgoland nach den Mitteilungen von Heufieberkranken und nach wissenschaftlichen Schriften* (cit. n. 34), pp. 20–27, on p. 21: “doch hat Dunbar eine Bindehautentzündung und starke Rötung des ganzen Augapfels als Folgeerscheinungen seines Pollantinpulvers im Jahre 1903 an mir selbst beobachtet.”

the disposal of Dr. Albrecht, the Secretary of the German Hay-Fever Association. I was agreeably surprised to learn that he himself had seen numerous cases in which Pollantin had not merely cured the attacks but had produced real immunization.”<sup>54</sup> Dunbar did not specify when his exchange with Albrecht took place. However, in the eleventh Heufieberbund report, issued in 1909, Albrecht began his discussion of hay fever and its remedies by alluding to new results from Dunbar. Laboratory experiments, he explained, had now proven that Pollantin worked. At the same time, the results from the Heufieberbund questionnaires were still unimpressive: only one-third of respondents had seen positive effects. Faced with this inconsistency between laboratory science and lived experience, Albrecht had the following solution: “To explain this contradiction, I would like to mention that 1/3 (!) of the patients who requested treatment from me for ‘hay fever’ in 1908, when examined closely, turned out to be suffering from a nervous rhinitis.”<sup>55</sup> Perhaps, then, many people who had self-diagnosed hay fever were wrong. Naturally, a specific antitoxin would not be of any use to those who did not truly suffer from sensitivity to pollen toxin! Dunbar’s isolation of the pollen toxin had not only opened up therapeutic possibilities but also offered an objective way of determining whether someone truly suffered from the disease. No longer did diagnosis have to rely on patients’ subjective sense of discomfort at certain times and in particular places. Instead, the physician could expose sufferers to a small amount of pollen toxin and observe their reactions. If a reaction followed, then it was true hay fever; otherwise, it might be just a neurosis. Albrecht’s argument represented a complete inversion of Mohr’s stance from just a few years earlier. Mohr had viewed laboratory and clinical research as tentative and had seen only the self-observed experiences of hay fever patients as real proof. Albrecht, on the other hand, presented a clinical test as more credible than subjective experience and suggested that such a test could disprove what the Heufieberbund members had observed in their own bodies. Albrecht was not alone: in the same year the *Medizinische Klinik*, a weekly newspaper for physicians in general practice, recommended the insertion of pollen extract into the eye as a state-of-the-art diagnostic tool.<sup>56</sup>

Pollen extract made a reaction test possible and helped to define “true” hay fever as an observable reaction to that particular substance. Although it would have been possible to contest the validity of the test, the gains from having the illness objectified as an independently observable, somatic illness appear to have been great enough for the organized hay fever patients to accept the loss of the subjective self-diagnosis. Without a method for clinical diagnosis, there was a risk that not only one-third but perhaps all hay fever patients might be dismissed as neurotic.

Similar struggles over the epistemic value of illness experience have regularly reemerged around later contested illnesses, as self-diagnosed patients have organized to demand that medical experts attend to and acknowledge their ailments. In the 1980s, sufferers of sick building syndrome drew from feminist ideology in their claims that embodied knowledge should be privileged over medical expertise. In relation to electromagnetic hypersensitivity, fibromyalgia, and chronic fatigue syndrome, attempts to develop tests and diagnostic criteria that disentangle them from the subjective claim of experienced illness have ended up at the center of controversies.<sup>57</sup>

<sup>54</sup> Keims, “Germs, Vaccines, and the Rise of Allergy” (cit. n. 14) (criticism and competition from other sources); and William Phillipps Dunbar, “The Present State of Our Knowledge of Hay-Fever,” *Journal of Hygiene*, 1913, 13:105–148, on pp. 141–142.

<sup>55</sup> Albrecht and Schultz, *Bericht XI nach den Mitteilungen von Heufieberkranken und nach wissenschaftlichen Schriften* (cit. n. 33), p. 7: “Zur Erklärung dieses Widerspruches möchte ich erwähnen, daß 1/3 (!) der Patienten, die als ‘Heufieberkranke’ im Jahre 1908 in meine Behandlung traten, sich bei genauer Untersuchung als mit nervöser Schnupfen . . . behaftet erwiesen.”

<sup>56</sup> Adolf Posselt, “Chronische Bronchialerkrankungen mit Ausschluß der Tuberkulose (Aertliche Fortbildungsvorträge),” *Medizinische Klinik: Wochenschrift für Praktische Ärzte*, 1909, 5:919–922.

<sup>57</sup> Murphy, *Sick Building Syndrome and the Problem of Uncertainty* (cit. n. 6), pp. 62–64; Christos Baliatsas *et al.*, “Idiopathic Environmental Intolerance Attributed to Electromagnetic Fields (IEI-EMF): A Systematic Review of Identifying Criteria,” *BMC*

Individual sensing and experiences of illness could not provide the kind of specificity that was needed to stabilize hay fever as an observable object in the scientific sense, which was ultimately what the Heufieberbund wanted to achieve. For hay fever to become objectified and hence acceptable in the medical mainstream, it had to be observable through some other means. The embodied experience had to be subjected to the demands of scientific objectivity, and the truth about the illness could no longer be generated from within but had to be interpreted through the lens of scientific instruments.

## CONCLUSION

In the Heufieberbund reports, the relationship between the subject and knowledge was in rapid transformation, and their repositioning in relation to each other took place in full view of a reading public. Early on, the organization attempted to stabilize hay fever as a discernible and knowable object through a circular accumulation of knowledge and sensation, meant to represent the experiences of individual bodies, as observed from within. Reading the reports trained the sufferers to recognize hay fever when it manifested in their bodies. What they were thus able to find flowed back into the reports, providing an increasingly clear image of the disease. In other words, the Heufieberbund reports are one instance in which “the private experiences of individuals have been made collective and turned into evidence.”<sup>58</sup> But observation also shaped individual experience. Along with other practices, such as seaside travel, the wearing of veils and nose plugs, and adherence to special rules for ventilation, laundry, and hygiene, the Heufieberbund cast observation and documentation as central components in experiencing hay fever.

The reports included findings from the professional medical sphere; however, at least initially, it was the afflicted body that resided at the center of the reports and contained the prime truth about hay fever. Surrounding it was the medical scholarship that communicated with the sick body and acted as a reference. The patient collective that made up the Heufieberbund engaged their bodies to test the theories developed in professional laboratories and clinics and passed judgment on the value of such theories in the (literal) field. Hence, for a few years, the Heufieberbund constituted an epistemic community with no boundaries between knowing and being known. Other actors in the hay fever field recognized the importance of that community. Even an esteemed medical researcher like William Dunbar was compelled to address their concerns and defend himself against their criticism. Thanks to commentaries in other channels, the self-observations that the Heufieberbund members recorded had an impact that was felt far beyond their own community.

For a brief moment, the Heufieberbund held on to the subjective experience of illness as containing a special truth. The firsthand experience of suffering within one’s body was held to be an important source of knowledge and could even be superior to the results produced by professional scientists and physicians in laboratory or clinical settings. Outside of the clinic and the laboratory was a world that was more real, and what individual patients experienced there was more important than the results produced in the artificial environment of a laboratory or clinic. Very soon, however, this outlook shifted to the complete opposite.

For hay fever to cease to be a contested illness and to enter medical science as a knowable object, its truth had to be disentangled from individual experience. Soon after the Heufieberbund

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*Public Health*, 2012, 12, art. 643, <https://doi.org/10.1186/1471-2458-12-643>; Sheng-Min Wang *et al.*, “Fibromyalgia Diagnosis: A Review of the Past, Present, and Future,” *Expert Review of Neurotherapeutics*, 2015, 15:667–679, <https://doi.org/10.1586/14737175.2015.1046841>; Kristin Barker, *The Fibromyalgia Story: Medical Authority and Women’s Worlds of Pain* (Philadelphia: Temple Univ. Press, 2005); and Joseph Dumit, “Illnesses You Have to Fight to Get: Facts as Forces in Uncertain, Emergent Illnesses,” *Soc. Sci. Med.*, 2006, 62:577–590, <https://doi.org/10.1016/j.socscimed.2005.06.018>.

<sup>58</sup> Daston and Lunbeck, *Histories of Scientific Observation* (cit. n. 37), p. 2.



formed, with the intention of making the disease known and accepted as a medical fact, professional medical researchers indeed began to study it systematically. These studies of the allergic body used tools of objectivity that made the disease appear more distinct, provided it with a solid core (the adverse reaction to pollen toxin), and established a way to observe it objectively from the outside (exposure to pollen toxin). Testing methods and tools developed in the laboratory setting competed with and eventually overtook the embodied experience—which then had to pass through science to become the truth about the body.

While enabling people to recognize hay fever in themselves through cultivated observational habits, the Heufieberbund reports also showed readers that they were part of a social group with shared interests, all carrying the same disease object within them. Herein lies the fundamental idea embodied in patient organizations: the idea of disease specificity, which enabled hay fever sufferers to experience themselves as a group and organize as such. Viewing the emergence of patient organizations from the standpoint of the late nineteenth and early twentieth centuries hence provides a clearer understanding of how illness became a foundation for building a community and organizing. Simultaneously, however, it reveals an inherent contradiction: the same notion of disease specificity that enabled patients to organize also dislocated the truth about illness from the body experiencing it, a development that became the bedrock of subsequent struggles over medical knowledge that found patient organizations among the main protagonists.