

7 Sam Berns: Progeria Between Clinical Trials and Lived Experience

The last chapter has given an overview over three different children living with progeria, suggesting that popular documentary may promote what I call successful impairment as an analogue concept to successful aging. This concept is taken up again in this chapter as I explore the construction of age(ing) as it connects to progeria. I focus on the 2013 HBO documentary *Life According to Sam*, depicting Sam Berns, a teenager with progeria from Boston. Here, the medium presents a crucial difference to the discussion of “Living with Progeria” in the previous chapter. While both sources are marketed as documentaries, “Living with Progeria” merely provides short five-minute glimpses into the individuals’ experience. Contrastingly, *Life According to Sam* is a full-length documentary, really zooming in on Sam Berns’ life, including his social and medical surroundings. *Life According to Sam* provides a subtler approach to living with progeria, trying to normalize life with the condition instead of pointing at its ‘difference.’ At the same time, the film raises awareness for the condition and presents itself as an advertisement for the PRF. It could then be accused of commodifying Berns in order to promote the research for a cure for progeria.

Much like the Vandeweert siblings discussed in the previous chapter, Sam Berns takes up the social role expected from a person whose institutionalized age moves within the teenage years: He is a student in junior high school, which dictates the way his stage in life is culturally imagined, as well as the social role he performs. Because of his aged body, on the other hand, the documentary portrays him as highly medicalized. It therefore depicts an area of extraordinary age(ing) that is often neglected within centenarian narratives and has only been touched upon in the previous chapter: Age and the biological, as well as the extraordinarily aged as a patient. *Life According to Sam* serves as an entry point to the inquiry of the biological as inextricably linked to social roles and cultural imaginaries. The connection between the cultural, the social, and the biological is especially prevalent in Sam Berns’ narrative as his parents are pediatricians and the founders of the PRF. They establish clinical trials and make it their goal to find a cure for progeria. This process is part of the documentary and provides insight into the connection between

the biological realms of Berns' aged body, its medical implications, and the way they affect his role in society, as well as the cultural imaginary attached to progeria.

Furthermore, *Life According to Sam* introduces a caretaker into the equation of extraordinary age. Whereas care persons were only marginally present within centenarian narratives (cf. Aldéa Pellerin-Cormier's daughter bringing her food), "Living with Progeria" touched upon the issue of care, especially in the part concerning Adalia Rose and the protective infrastructure surrounding her. The depiction in these instances, however, remained superficial, not elaborating on structures of care and the challenges an aged body may pose to everyday life. Contrastingly, in *Life According to Sam*, Berns' caretaker, his mother, is not only presented as his personal caretaker, but also as a savior and mother figure to all children with progeria. Consequently, she represents a core U.S. American ideal of motherhood and care taking, not only for her own son, but for an entire 'nation' of progeria patients and their families. The documentary renegotiates care as a public good but also raises questions about care and expectations of care not only concerning children with progeria but also 'old' people in general. The connection between Berns and his mother, as well as the fact that his mother runs the PRF and the first progeria drug trial, again, raise questions of age, agency, and disease: Is *Life According to Sam* truly his narrative or is he staged through the perspective of his mother and the PRF?

Within this chapter, I will explore how age is culturally constructed through its various subcategories, care, and medicine in *Life According to Sam*. Thereby, I will put a special focus on the depiction of the medical implications of the condition and therefore on children with progeria as patients. Furthermore, I will discuss how the documentary presents Berns as a child with progeria within the context of the search for a cure as an economic endeavor. First, I analyze the portrayal of progeria and the way it challenges dominant discourses about age(ing). I will then look at the connection between premature aging, aging in general, medicine, and the portrayal of Sam Berns' life within these categories. Subsequently, I will look at the clinical trial for a progeria treatment, inquiring how Berns' role as a patient influences his identity, as well as how the search for a treatment helps to stage progeria as an inclusive, transnational issue that concerns everyone. Lastly, by comparing the message of Sam Berns' TED Talk "My Philosophy for a Happy Life" to the way he is presented in the documentary, I will discuss the question of agency within the production of the documentary and its surrounding texts. Here, I will focus on the ways thinking about agency adds to a broader understanding, not only of the narrative itself but about its implications for the aging process.

7.1 Extraordinary Age in *Life According to Sam*

As discussed in the previous chapters, extraordinary forms of aging make age more visible in general by denaturalizing the narrative, that is, by deviating from the expected process and providing a surprising take on something that people take for granted. Progeria contributes to this denaturalization not only by disrupting normative expectations of the aging process but also by juxtaposing the different subcategories of age. Hence, progeria makes these subcategories visible and shows the circumstances in which one may be more important to an individual or the onlooking society than others. While these negotiations were present within all previous chapters, *Life According to Sam* allows for a more detailed examination, as the documentary often specifically addresses these juxtapositions. Because physical and outward age do not align with behavioral and institutionalized age, the case of Sam Berns serves as a point of inquiry for the observation of the interplay between different age subcategories in order to explore which subcategory has the power to determine a person's age in different situations. *Life According to Sam* portrays Berns' everyday life and the way he copes with his condition in various different settings. By challenging the way age is naturalized, his story questions the way age, and especially 'old' age, is culturally constructed in Western societies.

Berns' family's approach to progeria is established at the very beginning of the documentary through his father, who says “[w]e’re well aware of the prognosis [of progeria] but, you know what, we’re gonna stay optimistic because why wouldn’t we be? I mean, what are we gonna do? Like go into a shell?” (00:05:45-00:05:58). This attitude toward progeria sets Berns and his family apart from approaches to ‘old’ age. Although they know that the remaining life span is limited, they refuse to enter a ‘waiting room’ for death. Moreover, there does not appear to be a protective shell surrounding Sam Berns. While the narrative points to his physically aged body, it, at the same time, emphasizes that he and his family refuse to be defined by the cultural imaginaries that go along with it.

Similar to Adalia Rose, the first impression the audience gets of Sam Berns is, as it often is in every-day encounters, a visual one. Berns' portrait is featured on the documentary's DVD cover where he appears frail, has wrinkles, is bald, and wears glasses. Nonetheless, he is smiling and seems to be happy. His outward attributes taken together are visual indicators usually associated with an ‘old’ body. It is the appearance that causes the viewers to make initial assumptions about Berns' age. Without any further information, the spectator relies on the information given through his outward appearance. Consequently, because wrinkles and frailty are associated with ‘old’ age, he would most likely be categorized as such or at least not as ‘young.’

The DVD cover, at the same time, already indicates the reason for Berns' outward appearance as not being ‘old’ age but progeria. It says on the cover “progeria

is just a part of who I am.” Although no explanation is initially given about what progeria is, a hint is provided in connection to a disclaimer: The cover clarifies that the condition is just a part of Berns, indicating that for him at least it is completely normalized. This disclaimer is complemented by his smile, emphasizing his contentment with his situation. Judging the documentary by its cover would then suggest a less sensationalist approach to progeria than we have seen in “Living with Progeria.” Instead of focusing on what is distinctly ‘different,’ *Life According to Sam* seems to focus on progeria simply as a part of life.

Although Berns’ outward features are clearly caused by progeria, the film clarifies in its first minutes that “[w]hat is aging in Sam, is aging in all of us” (00:03:07). His disease does not only give him the visible features of an ‘old’ man but also weak bones, arthritis, and a cardiovascular system that would be expected in a person who has reached the institutionalized age of at least 80. This connection between progeria and the conditions associated with the ‘old’ body appears to be deliberately placed as it serves the purpose of promoting progeria research, which presents to be a crucial aspect of the documentary and will be further discussed in chapter 7.2.

Sam Berns’ body is put into the foreground again during the very first scene of the film where his aged hand is shown in a close-up shot as he plays with Legos (00:00:51). This shot can be read in two different ways. First, it can be seen as a juxtaposition of the aged body with ‘young’ behavior. His wrinkled hand, showing signs of arthritis, would be assumed to belong to an ‘old’ person, whereas playing with Legos is generally regarded as a children’s activity. In that sense, the action of engaging in a children’s activity would question the initial categorization of Berns as ‘old’ according to his physical and outward age. Hence, reading the scene in terms of the juxtaposition of age categories shows how different environments can emphasize different aspects of the constructions of age, questioning Berns’ initial appearance as ‘old.’ This reading is made more complex when thinking about the size of the Legos Berns works with. He puts together rather small parts which, if they were put together by an institutionalized aged person, would probably be considered a job well done and fall under the category ‘look at what this person is still able to do’ as seen in many centenarian narratives. The mere size of the Legos sparks the imaginary that what Berns does in this scene is not only unusual for an ‘old’ person but also mostly impossible. Berns’ body may be physically ‘old,’ yet, there is also an underlying emphasis on the things he can do despite his aged body which reminds strongly of centenarian narratives.

This ability of Berns’ body is connected to the second possible reading of the scene: It derives from the fact that playing with Legos could also be a therapeutic method to keep the arthritis-affected joints mobile. In that sense, the image of a hand that looks wrinkled and therefore ‘old’ could also be read as a promotion of the prevalent cultural imaginary of ‘old’ age as a phase of ‘second childhood.’ This phase of the human lifespan, according to Andrew W. Achenbaum, “signifies

diminishing physical and intellectual faculties with advancing years” (“Delineating Age” 301). In that sense, an ‘old’ person playing with Legos would contribute to the assumption that the very early and the very late stages of life are comparable in terms of physical abilities as well as mental capacities. According to this reading of the scene, it would still be Berns’ physicality that determines the way his age is constructed. To the audience, at that moment, he appears ‘old’ to the extent that he is unable to remain part of a midlife-sphere and has to return so his social role as a child. Here it becomes clear how physical age determines social roles through cultural imaginaries.

The latter reading of the scene, however, is deemed inappropriate by a voiceover in which Berns explains: “I didn’t put myself in front of you to have you feel bad for me. I put myself in front of you to let you know that you don’t need to feel bad for me because this is how... I want you to get to know me. This is my life and this... progeria is part of it. It’s not a major part of it, but it is part of it” (00:01:49-00:02:10). The audience learns the reason for his rapidly aging body, which explains that the action of playing with Legos is a juxtaposition to Berns’ aging body and not a way of coping with it through therapy. Consequently, in this initial scene, the audience is presented with the struggle of the subcategories of age: On the one hand, Berns would be considered to be ‘old’ through his physical and outward age, represented by the appearance of his arthritis struck hand. On the other hand, he would be considered ‘young’ according to his behavioral age as he plays with children’s toys.

The documentary here emphasizes the otherness *and* the sameness of Berns’ persona. By saying that what is aging in him is aging in everybody, it establishes him as part of a society that is worried by aging demographics and the prospect of decline. In contrast, the documentary encourages its audience to see the differences between Berns’ aging body and his social role as a child and thereby suggests an approach to the story that is not overshadowed by stereotypes surrounding the aging body. In that sense, all cultural connotations belonging to the aging body, such as immobility, decline, or death, are negated by the action of playing with Legos. At the same time, all connotations belonging to the action of playing with Legos, childhood and primarily health, are negated by the aging body. Finally, Berns’ statement again contributes to the normalization of his condition in general. He does not want pity or preferential treatment. He wants to explain his condition so that it can be normalized within society. Ironically, Berns advocates for the absence of what makes his narrative so interesting for this study: He wants his extraordinary age to become ordinary and therefore invisible, as well.

Berns’ behavioral age adds yet another nuance to the image of his age through his description of progeria. He describes the condition as a part of his life, yet not a major one. He actively positions his life in a way that distances him from the overwhelming associations going along with the aging body. His statement

therefore counters all assumptions people could make about his life and his abilities due to his physical age by foregrounding his behavioral age. This works against the cultural imaginary of 'old' age and questions the power the aging body should have in this construct.

By challenging the role physical abilities should have in the construction of the self, Berns' narrative asks its audience to see the value in the aging body. This demand for a value-centered view on the body, connects back to Sally Chivers' demand of, in reference to disability studies, accepting deviating bodies as "different ways of being in the world" which can be "sources of knowledge, satisfaction, creativity, and happiness" (*The Silvering Screen* 9). Accordingly, the field of disability studies, so it could be argued, is one step ahead of aging studies in acknowledging the value and meaning in bodies that deviate from a supposed norm. In the sense of disability studies, the simple act of playing with Legos and being hopeful despite his aging body can be read as an attempt to view the aging body in exactly the way Chivers proposes. Berns' narrative thus challenges Western societies' derogatory assumptions of the aging body precisely by not portraying it as negative but merely as 'there.' Ultimately, to see both binary oppositions of 'young' and 'old' within one individual fosters an understanding of this binary being a mere cultural imaginary and that, in turn, the negative image of the aging body could be redefined along the lines of value and knowledge. To reinforce Berns' initial statement, throughout the film, he is often shown in environments that are generally associated with youth. He appears in class with his friends, talking about homework assignments and projects or, he is shown at a rock concert. Hence, the film underlines that, in everyday life, his physical age is not given the power to majorly interfere with his behavioral age. Conclusively, the cultural connotations of the aging body are objected by his social status as a student. In those instances, the physical state of his body does not seem to be important. It is through this focus that Berns' physical age is undermined whereas his behavioral age is maintained and even enhanced.

As opposed to the images provided in the initial scenes, the film also shows situations where Berns' physical age is placed at the center of attention. A large portion of the documentary deals with his mother, Leslie Gordon, and her quest to find a cure for progeria and, ultimately, a medication that slows down the aging process in all people.¹ To do so, the documentary accompanies Sam Berns through

1 This is again tied to the assumption that studying extraordinary forms of aging medically might help to gain insight to the general process of aging. It is stated on the HBO homepage, promoting the documentary that "gaining a better understanding of how the disease works could lead to breakthroughs in treating heart disease and aging in the general population" ("Life According to Sam: About"). Researching progeria thus is not only the starting point of my research, it is also used as a promotional tool, toying with societies wish to undo aging and to find eternal youth. This point will be further elaborated on in chapter 7.2.

his required hospital visits, showing the processes of examinations and attempts at treatments. These scenes foreground his physical age. During his treatments, he is separated from his life, which foreshadows the social isolation that the later part of life supposedly brings with itself. About his experiences in the hospital Berns says: “When I’m in the hospital, I’m isolated from friends, I’m isolated from television, I’m isolated from my home, I’m isolated from my cats. It’s like I lose all of the things that make me me, except for progeria” (00:52:48-00:53:34). What Berns describes here is disengagement as his aging body forces him to spend time in the hospital where he has to deal with nothing but the signs of ‘old’ age. Hence, the progeria body has a similar effect on Berns as the aging body is supposed to have on the elderly. It is in these moments in the hospital that physical age becomes Berns’ defining feature and he is, like the elderly population, associated with decline. He thus falls victim to disengagement, yet a disengagement that is specific to time and place. The audience knows that his state of isolation is only prevalent in the specific context he finds himself in. Here, again, it becomes obvious how certain social and cultural contexts influence the significance of a given category of difference. That is, the context of the hospital enhances the prevalence of Berns’ physical age, while withdrawing the determining power of his behavioral age which then influences his self-identification: The way Berns feels and identifies in relation to his aged body differs from situations in the hospital to situations in school, for instance.

The encouragement to rethink assumptions about the aging body becomes even more prominent in a later scene when Berns tries out for his school’s marching band (01:06:30-01:10:50, 01:28:47-01:30:48). Here again his youthful behavior, the wish to play in a marching band and the drive to do everything humanly possible to achieve that goal, is juxtaposed to the restrictions he faces due to his physical condition in terms of being able to march in sync with the band and play or even carry the drum. Nevertheless, he is determined to make his dream come true and his parents find a way to design a lighter harness for the drum, giving him the chance to participate in the band. In that instance, his performance shows that it is not necessarily the body itself that keeps individuals from participating in certain activities. Rather, it is the way these activities are designed within a given society. In pursuing this argument, Chivers suggests that “[a] person in a wheelchair may not be able to navigate stairs, but that is a challenge only in a society that builds stairs, rather than ramps” (*From Old Woman* xxix). Accordingly, being physically weaker than others is only a problem for Berns because he lives in a society that builds heavy harnesses in the first place. His efforts and the efforts made on his behalf are attempts to encourage society to become more inclusive for all kinds of different bodies, including the ‘old’ one. Further, it becomes obvious that, in certain environments, Berns’ aging body is not a victim to disengagement from society of which he is an active part. Conversely, the narrative of Sam Berns shows that the aging body alone cannot keep him from participating in social activities.

The lesson the documentary teaches its audience is that there are means to keep the negative connotations of the aging body and their impacts on later life at bay. This possibility should be transferable to the elderly as well. Since it is possible for a child with progeria to overcome the boundaries of the aged body, why should the elderly not be able to do the same if they want to?

It is, in that connection, only because the documentary shows Berns' life in that particular light, that the call for a treatment for progeria is legitimate. His quest for meaning and happiness emphasizes the need to help children with progeria. This medical argument then brings back the notion of 'old' age as a disease and it is important to bear in mind that, in this special case, 'old' physical age truly is a disease. In that connection, the documentary can be read in two different ways. Besides the positive aspects of suggesting that the aging body can lose the burden of its cultural connotations through the emphasis of other aspects in life, it also implies that an attempt to 'cure' aging would be an idea to be welcomed. Accordingly, the flipside of the narrative reveals that focusing on Berns' behavioral age, serves the purpose of supporting his request for a longer life. In other words, only because he is acting and feeling 'young,' the spectator is inclined to believe that it is necessary to search for a cure in the first place. This, in turn, shows that, drawing on one category of difference while withdrawing another, when done deliberately, always serves a purpose, in this case the purpose of promoting the efforts to find a cure for progeria and ultimately, to prolong the human lifespan.

Despite these very different approaches to the documentary, the narrative works toward a deeper understanding of the aging body and implies that there is a possibility for meaning and value in life, even towards the end of it. This is why it is important to reveal that Berns' behavioral age is used in many instances to overwrite his physical age. In this very context then, Berns serves as an example for a progress narrative. Sam Berns fights decline by highlighting his possibilities. Additionally, his example shows that aging is not a matter of black and white. Having an aged body might restrict a person from engaging in certain activities but it does not restrict that person from being happy and leading a meaningful (later) life. Looking at the construction of age(ing) in *Life According to Sam* shows that for him, physical age is not the determining factor of his life, unless he is put into situations that make him focus on that subcategory of his age. Further, comparing the way extraordinary age is constructed in this narrative to accounts of centenarians already touches upon a major issue: physical 'old' age being accepted as part one's life may only be possible if the other two age categories are not considered to be 'old.' 'Old' people, on the other hand, can be regarded as being constantly put into situations in which their physical age is foregrounded.

7.2 Progeria and Clinical Trials

Despite the general depiction of Berns' life and, connected to that, his extraordinary age, one main theme in *Life According to Sam* is the search for a cure—or at least a treatment—for progeria. The documentary does not only touch upon the general endeavor of the PRF but also on the early trials for a treatment. Thereby, it becomes a medical narrative, exploring the ethical realms of drug trials, as well as the human stories behind them. In that connection, this narrative becomes a piece that strongly advocates for a human rights cause. Here, it can be related back to Schaffer and Smith's assumption that life narratives concerning ethical issues and justice implicitly aim to provoke a response in their audience (3). Telling the story of a clinical trial may evoke the wish within the audience that the treatment will be marketed, as long as the process is depicted as just and ethical. Berns' parents, who founded the PRF and are both pediatricians use the film as a platform to elaborate on their quest for a cure. The emphasis on the similarities between the progeria body and the aging body serve as an appropriation for their research as it promises to help the aging population in general. The documentary only depicts the early stages of human trials, culminating in a publication of the results and therefore the starting point of the FDA's review process.² While this is a tremendous breakthrough, the documentary does not point towards the lengthy process that will have to follow to get the treatment approved for general use. The audience is inclined to think that the fight has been won, yet the drug depicted in the documentary has only been approved in November 2020, seven years after the documentary's release, as the first ever treatment for progeria ("First Treatment").

The drug trial only comes into being because Berns' parents are pediatricians and have the means to do the research themselves. The documentary touches upon their personal fight to find a cure that was initiated with Berns' diagnosis. Although both parents are physicians themselves, their quest for a diagnosis remains a substantial struggle. This common trope within progeria narratives is incorporated into a family history of how Leslie Gordon and Scott Berns met and had their first and only child. While the story of the couple's first meeting is told by Sam, the story of his diagnosis is narrated by his parents:

2 The FDA clinical trial process is divided into four phases, the first testing for toxicity and dosage in healthy people, the second testing for side effects and first signs of efficiency, the third testing for efficacy, and the fourth testing for safety and efficiency. Each stage is accompanied by a review process (US Department of Health and Human Services).

Leslie Gordon: When Sam was born, to us he looked normal but even when we look back, we can see something that just wasn't right. And we went to our pediatrician, and we kept saying something's wrong, something's wrong.

Scott Berns: He wasn't really gaining weight over that first year and a half and we attributed that initially to the fact that he didn't eat as much, he spit up and babies spit up, right? And I noticed there were things about his skin that I would think 'this is a little bit different around his stomach and what's that all about?' And we are both physicians, so I was like 'oh, maybe we're being too sensitive about noticing some of these things.'

Leslie Gordon: It just came from my soul, like 'something is going on here.' It was incredibly frustrating. Finally, a brilliant friend and colleague of ours came up with this idea that Sam might have progeria. (00:28:25-00:29:30)

The point I would like to make is connected to narrative structure. Sam Berns elaborates on his parent's relationship, while they tell the story of his diagnosis. This intertwines both storylines as the parents speak about the son and the son speaks about the parents. Although they are interviewed individually, they are presented as an inextricably linked unity. Moreover, Sam's story becomes the story of his parents and vice versa. This specifically shows how progeria is not the issue of an individual but of an entire family: Sam's illness is also his parent's illness.

Besides stressing the communal aspect of progeria, the story of Sam's diagnosis reflects a certain helplessness on part of his parents. Although, or especially because they are physicians, they are not sure what to make of their son's symptoms. They are even hesitant in their narration, indicating that they are unsure whether they always handled things right. Scott Berns, for instance, needs to reassure himself that it is normal for babies to spit up, thus justifying why he did not initially worry about his son. Ultimately, this story tells a gradual process of figuring out that there is something wrong in the first place and then defining what exactly this might be. Sam's diagnosis is not a sudden metagnosis for his parents but a slow break in identity and the grappling with the notion of something being wrong after all. This slow process from regarding their child as perfect, to sensing an illness, to finally diagnosing Sam with progeria is depicted as a pivotal procedure in the family's identity from average to a family of fighters. It is this change in identity that leads to Gordon's quest to find a cure for progeria, initiating the clinical trial.

In addition to presenting the diagnoses or gradual, extended metagnosis of Sam Berns and his family, the narrative dedicates a substantial amount of time to the depiction of the progeria drug trial. Depicting both these processes provides hope, not only for the children represented but also for every person who may be scared of the aging process. According to Daniel Callahan, "[h]ope drives good medical care, for the physician and the patient" and nowadays, "[h]ope also drives the war against aging and disease" (91). He thus indicates that hope is the motor

that initiates improvement in health care and medical practice. In the case of Berns' parents, this is certainly the case, as their hope to save their son sparks their interest in the research they are doing. Hence, hope is needed to strive for a better health and to fight conditions even if they seem hopeless. For Callahan, it is this promotion of hope that makes "[t]he present period . . . a revolt against death itself" (90). This quote also speaks to the human hubris of thinking all diseases ultimately will be curable. Furthermore, as 'old' age is considered a 'waiting room' for death, revolting against death itself is inherently also a revolt against the aging process.

The clinical trial is depicted from two different perspectives: the perspective of Leslie Gordon, Sam Berns' mother, as the researcher in charge of the trial and that of Sam Berns as a patient within trial. Gordon's perspective is a rather scientific one. She is the educator, explaining to the audience how the disease affects the human body, as well as how clinical trials in general and the progeria trial in particular work. She narrates the trial, explains how the experimental drug is supposed to work, and what medical and ethical risks are part of the endeavor. Thereby, she also becomes an advocate for progeria research in general. The documentary shows that, in order to make this research happen it needs a person educated within the field of medicine who is willing to dedicate all her time and energy into this project. With the low number of progeria cases worldwide, it is not surprising that this person had not been found before Gordon started her endeavor which, of course, was also a highly personal one. This is also connected to a lack of money. As becomes clear in the documentary, clinical trials for conditions only affecting a few people lack funding. Therefore, the constant reference to progeria and its relatability to all aging processes becomes all the more important, as it makes Gordon's research beneficial for the entire human population. Nonetheless, Gordon stresses her role as an advocate for children with progeria. When elaborating on her research and its benefits for humanity, she states that "the aging fields will take this and run with it, but my job, my passion, is to stick with these kids" (00:24:53-00:25:03). While she uncovered a biological mechanism that may benefit aging research tremendously, she sees herself as responsible to prioritize progeria research above else. Gordon thus becomes the personified hope for children with progeria and their families.

Although Gordon has a personal connection to the trial, in reference to it, she is depicted as researcher and an advocate for the progeria community first and Sam Berns' mother second. Therefore, her perspective is a professional one. Berns, on the other hand is depicted as the patient whose personal connection is inevitable, as the trial directly affects his body and his identity. Whereas his mother's account is also always connected to the fact that she is trying to save her son, her narrative focuses much more on the scientific and ethical aspects of the trial. Sam Berns' account, on the other hand, is nothing but personal. As mentioned above, he feels that being at the hospital deprives him of everything that defines his identity (00:52:48-00:53:34). The clinical trial and the connected examinations are thus an unwelcome

reminder of his condition that is otherwise in the background of his life. Nevertheless, he understands the importance of the trial and the fact that the time he spends at the hospital may ultimately lead to him improving. His hope, which is ultimately a representative for the hope of all children with progeria and their families and friends, is rewarded when he gets the results of his trial and the physician states that his “numbers are phenomenal” (01:24:25). Consequently, all the hardship and the temporary loss of identity have been worth it because, according to the trial results, the treatment is working. Berns then overcomes his role as a mere patient and becomes a character who has successfully fought his condition.

Connected to this, Berns points out that due to the trial he now understands his condition better and thus can move forward: “I feel like now progeria is more known, I know more about it genetically. So, it’s less of an embodiment now. It used to be that thing that prevents me from doing all this stuff that causes other kids to die that causes everybody to be stressed and now, you know, it’s a protein that is abnormal but we can subtract ourselves” (01:29:40–01:30:11). Once he knows about the biology of his condition, it is less of a burden in his life. This implies that society needs education, not only in terms of renegotiation cultural imaginaries but also in terms of understanding the biology of a condition to move forward. His identity is no longer tied to the unknown or a vague metaphor. Rather, for him, knowing more about his condition has the power to normalize it. Hence, things that are considered to be ‘different’ need to be normalized through knowledge. This does not mean that we do not acknowledge that there are differences, rather, that we accept that there is no norm. If understanding the biology of his condition helps Berns to move on, it may also help people to move on if they find out more about the biology of aging. I would argue, however, that it is not only the biology that we need knowledge of in order to overcome, but that we need cultural knowledge of these issues as well. In that sense, this documentary provides knowledge about the biology and knowledge about life with this condition, hence, normalizing both. This line of argument then points to a general need for more diverse representations in all areas of life in order to provide cultural knowledge of lives that deviate from a supposed norm.

Besides focusing on the implications of the trial with regard to the aging body as well as illness and medicine in general, the documentary reinforces the transnationality of illness and, implicitly, also of aging. When it comes to the depiction of the trial it quickly becomes obvious that there are families from all over the world participating. Hence, children with progeria and their families from all over the world come to Boston in order to be part of the trial and to share the hope provided by Leslie Gordon. Consequently, she is not only helping her son, but she is also helping the world. While she is thus not primarily depicted as a mother to Sam Berns in the context of the trial, she is presented as a motherly figure to a community of children with progeria. This does not only emphasize the sense of a common

effort towards finding a cure but also enforces a universality of the condition: This can happen to anyone. Gordon then uses her mother role in order to emphasize this universality not only of the disease but also of her motherly role within it. She explains that “[p]eople will say things like ‘I don’t know if I could do this’ and my answer to them is ‘yes, you could’” (00:04:33–00:04:38). She thus tones her own achievements down and humbly implies that everyone would act the way she does in her situation. In combination with the transnationality of the clinical trial, she becomes an icon of a community who is not only humble but a pioneer in research, leading the entire world to success. In the U.S., this speaks to a national self-image of progress and American exceptionalism. Staging researchers from the U.S. as the leaders who will solve a worldwide problem adds to the inclusion of the audience into the general ideology of the narrative. In that sense, Gordon becomes a pioneer, leading an expedition into unknown territory of progeria, a role model for the rest of the world to look up to. In that sense, her role echoes U.S. cultural tropes of Winthrop’s “city upon a hill” (121) with all eyes and hopes on her and her trial. Through emphasizing the trial as a transnational endeavor with United States researchers at the front lines, the documentary thus evokes a sense of national pride connected to it.

Moreover, depicting progeria as a global phenomenon evokes a sense of community that counters the often-depicted narrative of illness and individual overcoming. Rather, Leslie Gordon advocates a communal approach to the disease, which in turn forms an infrastructure of support. At the same time, the connection between progeria and aging in general suggests the question whether, if progeria is addressed as a worldwide issue, aging should be as well. If so, one could argue that not only the medical but also the social and cultural aspects of age(ing) need to be regarded from a transnational angle in order to understand the cultural processes surrounding it.

Discussing the progeria clinical trial shows how *Life According to Sam* is not only a narrative of Sam Berns’ life but also a narrative of a human rights claim for a treatment of a terminal disease. Thereby, the trial narrative shows how disease and treatment influence a person’s identity, as it forces people to become patients and exist in environments where the condition is the center of their entire being. It puts Leslie Gordon in the position of an U.S. American hero who sets out to save the world, implying that she will not only save children with progeria but the aging population as well. This narrative implicitly plays on a general fear of dying within its audience, supporting the claim for the necessity of a cure for progeria all the more prominent. Nonetheless, the depiction of the trial offers perspectives on approaches to the aged body in general: There is a need for diverse narratives of all bodies, including age(ing) bodies, in order to establish a cultural imagery that defies notions of a powerful norm. According to this understanding, all bodies

would be considered 'different' as all experiences are unique, ultimately challenging norms in general.

7.3 A Philosophy for a Happy Life: Sam Berns' TED Talk

Besides being part of the documentary about his own life, at the age of 17 Berns gave a TED talk called "My Philosophy for a Happy Life." Whereas documentary and TED talk were published in the same year, listening to Berns' elaborations in the talk indicates that filming the documentary took place or at least had begun four years prior ("My Philosophy" 09:45). This talk does not only present the opportunity for a now matured Sam Berns to share his perspective on life, but also it can be read as a marketing strategy in order to promote the documentary. Both aspects will be discussed in further detail in chapter 7.4 concerning voice, agency, and perspective in *Life According to Sam*, as well as in Berns' TED talk. This current chapter focuses on the contents of this talk and the implications it makes toward Berns' aging process as well as the aging process in general. By looking at Berns' philosophy and reading it against the grain his inclusiveness of the broader population becomes the excluding factor for 'old' people. The TED talk here implies is that there is a line between 'old' people and the rest of the world that has nothing to do with the aging body.

The core message of Berns' TED talk clearly is that, deep down, he is just like any other person on this planet, thus countering imaginaries presented by narratives like "Living with Progeria." This message is incorporated into his philosophy for a happy life which is based on four elements:

- Be OK with what you ultimately can't do because there's so much that you CAN do
- Surround yourself with people you want to be around
- Keep moving forward
- Never miss a party if you can help it (12:16)

All these aspects relate to the everyday life of the audience but are intensified by the fact that the narrator has a terminal disease. Moreover, reading this advice against the grain offers many insights into the way the aged body is regarded within society and at the same time provides a criticism of the very same.

The first point on Berns' list refers to a focus on a person's ability in acceptance of restrictions. Reading it with Berns' condition in mind, this becomes a powerful statement which is reinforced by telling the story of him joining his school's marching band, mentioned above. Berns makes clear that progeria is something he does not constantly think about. In other words: He is not his condition. This

is directly connected to scenes in the documentary where he states that progeria does not define him. In that instance, the messages given within the documentary and within the TED talk align: Berns' physical age does not restrict him from many things he wants to do. However, he specifies that "sometimes [he] need[s] to find a different way to do something" (Berns 04:05). In other words, there are some things that he needs to work hard for or find compromises. Connected to that, by telling the story of the things he *can* do once he has put some effort into them, he sparks a thought process: Are there not things in life for every person that they cannot do or have to work harder for than others? For instance, not everybody can join a marching band. This does not have to be due to physical restrictions but may be due to a lack of musicality. If I cannot play the trumpet, I will not be successful in trying out for playing trumpet in a band, and if I do not have the rhythm and the hearing for it, I may have a very difficult time to learn playing the trumpet. These different talents and abilities in every individual are often taken for granted. Only if there is a label such as disease, disability, or 'old' age assigned to this inability, it becomes a stigma. If Berns indicates over and over again that his body and therefore his physical age is not connected to his identity, this same claim can be made for 'old' people. Yet, popular narratives suggest the opposite: Only an able, 'young' body can be an acceptable body. Here, again, the narrative highlights what Chivers has argued: For disabled bodies there are advocates claiming their value, while for the aged body society seems to be stuck with the assumption that every value is deeply connected to physical ability.

The second element of Berns' philosophy is rather straight forward: If you surround yourself with the people you love, life is always better. Again, this advice is applicable to most lives and therefore underlines Berns' sameness to the rest of society. However, connecting this point to narratives previously discussed shows that choosing the people you surround yourself with, often is a privilege. Looking at Aldéa Pellerin-Cormier, George Dawson, and Adalia Rose shows that sometimes people are not able to choose the people to surround themselves with. This may be due to their institutionalized age or their physical age or, more broadly, due to their interdependence. All three individuals cannot go anywhere by themselves and have to rely on others. Especially in the case of the centenarians, most friends and siblings have passed away. Family members have their own lives and people *they* want to surround themselves with. Irrespective of physical ability, there seem to be more possibilities for 'young' people to mingle with peers. This points to the general assumption that the need for social activity is thought to be absent in 'old' people. What reading Berns' philosophy against the grain shows then, is that the very privilege of deciding who you want to spent time with, is a privilege of the 'young' and able-bodied.

The third point on his list clearly refers to the future and something to look forward to. Although 'old' age (especially 'old' physical age) in public imaginary is

inextricably linked to a lack of future, Berns defies this notion. Instead of imagining himself in a ‘waiting room’ of the ‘old,’ he emphasizes the need to look ahead. This need for a sense of a future appeared to be crucial within centenarian narratives as well and, according to Lindberg and Marshal is a key element of successful aging. This sense of future thus emphasizes the sense of successful impairment surrounding Sam Berns. Moreover, by sticking to a future oriented mindset, Berns does what experts suggest for a meaningful life (cf. Edmondson). However, this also raises the question whether his orientation towards the future is socially more acceptable because of his ‘young’ institutionalized and behavioral age. Especially the latter could be a significant factor within this part of his philosophy: It may be considered ‘young’ behavior to orient oneself toward the future, making it sanctionable for those considered to be ‘old’ to do the same.

The fourth and last point of Berns’ philosophy may seem rather trivial, but it is the only one that cannot be read in terms of age or ability. Rather, Berns gives advice here that only applies to extrovert people who like to party, drawing an implicit line of inclusion—not with age but with character. Nonetheless, as this TED talk shows, the emphasis on physical age and physical restrictions is deeply connected to institutionalized age. Physical decline is thus a bigger issue with the increase of the number of years a person has lived. This is intensified by social structures and support systems that support ‘young’ people not only in the four points Berns deems necessary for a happy life but in general. Ultimately, in his TED talk Berns reinforces his sameness to the general population, thereby often excluding ‘old’ people.

7.4 Sam Berns as Commodity: Agency and Perspective in *Life According to Sam*

The previous chapters have shown that agency can have many forms and connotations. Macklemore’s grandmother, Helen, is merely shown and staged by her grandson and does not get to speak at all, which presents as rather straight forward denial of agency in terms of voice. Aldéa Pellerin-Cormier gets to speak but she is only given the chance to talk about questions that have been asked by the producers who therefore set the tone and the direction of the narrative. George Dawson’s case is the most complex one, since agency is intertwined with authorship and co-authorship, as these issues are directly addressed within the narrative itself as well as the surrounding para-texts. In Adalia Rose’s story, it especially was a form of medical agency that seems to be taken from her, as she is denied her own voice or even knowledge in important matters for purposes of protection. The Vandeweert sibling’s agency is tied to institutionalized age and gender, providing 21-year-old Michiel with power over the narrative, while keeping 12-year-old Amber

in the background. Thus far, all examples discussed have shown that agency often lies with the middle-aged, depriving the audience of narratives of aging—and in this case specifically of extraordinary aging—of the unadulterated voice of the extraordinarily aged. Hence, the audiences of the various narratives do not get to see stories that are untinged by the expectations of others; that is, untinged by the imaginations and causes of a middle-aged understanding of the aging process. Here, middle age becomes the cultural norm, the one in power, glossing over individuals' perspectives and romanticizing their stories.

While in *Life According to Sam* similar mechanisms apply, there are several points that this narrative specifically adds to the discussion of agency in terms of age(ing). Berns' story is as carefully orchestrated by different agents as the narratives previously discussed. However, these mechanisms do not solely aim at showing that a great life is possible despite or because of extraordinary age. Rather the purpose is finding a treatment for an illness. I am thus interested in the way Sam Berns' agency appears to be different because of this different aim of his narrative. In what way is Berns commodified not as a paragon of aging, but as a paragon of patients or paragon of illness and what is his own take regarding these mechanisms? In order to discuss these questions, I will not only consult the documentary itself but also refer back to Berns' TED talk, which is included in the extras of the documentary's DVD. I will read the message he aims to convey within his TED talk against the message of the documentary as a whole.

As mentioned in the introduction of this chapter, *Life According to Sam* was produced for the pay TV channel HBO and promotes the medical search for a treatment for progeria. When it comes to agency within the narrative, there are several components at stake. First of all, HBO wants to produce contents that make people subscribe to their channel. The documentary therefore needs to speak to a wide audience and tell a story that they can relate to which the narrative achieves in various ways. As Schaffer and Smith argue, “[p]ublishing houses . . . convert stories of suffering and survival into commodified experiences for general audiences with diverse desires and also for an increasing number of niche audiences interested in particular kinds of suffering” (23). HBO, as the institution that would be considered the publishing house in the world of television, needs to make sure Berns' experience is understandable and relatable for all kinds of audiences. This is achieved through the focus on the universality of the aging process, since, no matter where you are from and what (sub)culture you belong to, you age. Therefore, as mentioned above, in the first few minutes of the documentary, on-screen lettering appears, informing the audience that “[w]hat is aging in Sam, is aging in all of us” (00:03:07). This is a recurring theme throughout all progeria narratives, as relatability presents one of the core needs for generating in audience in the first place. At the same time, this relatability in terms of the aging process ties in with the second aim of the documentary: to generate support for a cure. This second

aim is the main goal of the PRF, an organization in need of funding in order to continue their research. Here, the interests align perfectly, as reinforcing the need for a cure works through the constant emphasis on the universality of the aging process.

The second mechanism to achieve relatability with the audience is the use of common tropes of U.S. American culture and history.³ As mentioned above, Leslie Gordon is presented as a pioneer in research, leading the whole world into a better future. Moreover, like George Dawson's narrative, one way to regard Sam Berns' story is as an example of the American Dream. Berns is portrayed as a perfect student, helping his classmates with difficult tasks (00:06:19-00:06:45) and receiving numerous awards for outstanding achievements at his middle school graduation (01:01:04-01:02:05). Furthermore, he is presented with a very positive attitude towards life which triggers ideas of overcoming all odds and achieving the previously considered impossible which are mechanisms inherent to the myth of the American Dream. This connection is intensified when Berns tries out for his High School's marching band. Although it looks like he cannot join the band initially, he, or much rather his mother, finds a solution of having a custom-made harness so Berns can join the band after all. These instances of overcoming are ever present in the narrative and are deeply connected to an U.S. American cultural understanding. This, in turn, makes Berns' narrative a typical US American one and, therefore, highly relatable to an U.S. American audience. These two major currents within the narrative contribute to making this documentary a sellable one.

The second important agent within this narrative is the PRF, represented by Berns' mother, and the search for a treatment and, inextricably linked to that, support from society, especially financially, as the PRF is also funded by private donations ("Give"). It surely is no coincidence that besides Berns' TED talk, the only other extra material provided on the DVD is an introduction to the PRF. As mentioned above, the relatability of progeria to 'old' age is certainly a strand of the narrative that is emphasized by their take as well.

Consequently, two very strong agents have their stakes in what *Life According to Sam* should look like in order to be sellable. These elaborations are not meant to excoriate either HBO as a network or the PRF and their search for the cure. Especially the latter fulfills a highly important purpose that is surely worthy of support. Rather, this discussion aims at showing the powerful mechanisms behind the narrative in order to shed light on the means and aims of its production. Ultimately, looking at these two corporate aims of the documentary, inevitably leads to the question what role and what voice Sam Berns has in his own story. Within

3 The documentary is available worldwide. Yet, HBO as a pay TV channel is foremost consumable in North America. Hence, it is specifically important to speak to this target audience and include them by the use of common cultural tropes.

the documentary, Sam gets to speak for himself, yet, he is presumably also bound to the questions he is asked. He appears knowledgeable about his condition and what it entails for his life and the life of his friends. Although his mother is very protective of him, he does not appear to live within a protective bubble. Rather, he goes to a public school, plays in his school's band, and visits concerts with his father. The interview mechanisms, as opposed to Rose's narrative, are very different. For instance, Berns is interviewed on his own, without his parents and gets to speak about his condition and his take on life. While he potentially has no say in the images that are broadcasted or the way the narrative unfolds, at least he is not censored in a way that denies him his own take on his story completely.

Whereas the documentary consists of the aims of others, Berns' TED talk may give a clearer picture of his own take on life and his condition. Looking at the TED talk as a comparative narrative is fruitful for the discussion of agency for two main reasons: First, the TED talk can be assumed to be closer to the core message that Berns wants to bring across and is thus closer to what appears important for the extraordinarily aged individual. This message, with all its implications read with and against the grain have been thoroughly discussed in the previous chapter. Here, it is important to add that Berns' TED talk, in his core message, aims at a similar message as the PRF: We are all the same and we are all in this together. This may also be, because Berns himself holds stakes in the quest for a cure for progeria. He is the person in this narrative who will profit from a drug that may prolong his life. However, while the PRF's message focuses on the medical standpoint, specifically including 'old' people, reminding its audience that everybody ages, the TED talk brings this to a social level. Berns indicates that every individual can have a happy and meaningful life by following his simple steps. Second, in his TED talk, Berns retells one of the storylines included in the documentary: the narrative of him wanting to join the marching band. Hence, this talk offers the unique opportunity to compare the focus of the two narratives and thus discuss their respective aim and intention.

The second point presents to be the most interesting one in terms of narrative agency and perspective because the marching band story provides the same storyline, told from two different angles. In the documentary, it is mostly Berns' mother who advocates with his teacher to give him a chance in the band. There are scenes in which the mother is cooped up in the teacher's office with him discussing options. Berns, at the same time is shown trying out for the band and coming to his mother with his problems. While trying out for the band, his mother is close by and when he is unable to carry the harness with the drum, he approaches her right away:

Sam Berns: I can't march with this thing on.

Leslie Gordon: [Removing the harness and the drum from his shoulders] Do the motions without the drum. Go ahead. (01:06:08-01:06:16)

While Gordon is depicted as a person who solves problems quickly and efficiently, Berns, in this very scene, is not an active agent but a helpless child. This depiction is of course necessary in order to stage his mother as *the* mother figure for all, as the heroine who will ultimately save all children with progeria.

In Berns' own narrative, however, the wording he uses puts himself into the position of the fighter. For instance, he explains that when it comes to playing in the drum line, "nothing was going to stop [him] from playing snare drum with the marching band" (01:20-01:21). In the original, he obviously uses "me" which indicates his own willingness and drive to overcome his problems. This is a stark contrast to the way the narrative is framed within the documentary as it shifts the focus away from Berns' support system onto him. This shift provides him with agency. At the same time, in the TED talk, one could argue, Berns undermines the importance care and support play in the fulfillment of his philosophy. However, he does not claim full credit for overcoming his snare drum problem, as he states "my family and I worked with an engineer to design a snare drum harness that would be lighter and easier for me to carry" (01:26-01:32), thus acknowledging that this was a common effort. Neither the TED talk, nor the documentary specify whose initiative it was to approach an engineer. However, untangling the mechanisms behind this is only of secondary importance as comparing the two narratives shows that there is a break between the depicted agency when it comes to the marching band storyline. In connection to that, the importance of this part of the story for Berns becomes much clearer in the TED talk. It is not only presented as his personal achievement, but also the very first thing he tells his audience—a story of success, proving that his philosophy works. In the documentary, on the other hand, the marching band storyline is just one of many stories told about Berns' life.

Besides these two main points of the inquiry in this subchapter, I would like to briefly turn my discussion towards the issue of Berns' own perspective within the TED talk, as opposed to the documentary. In addition to reusing the marching band story, Berns references one other part of the documentary: the pivotal moment where, through a better understanding of the medicine, he gains a better sense of his life and can move forward and away from progeria. This scene, that has been discussed in chapter 7.3, is cut into Berns' talk, including his own statements from the documentary. Consequently, Berns shows that there are instances where his own narrative aligns completely with what is shown in the documentary. In other instances, he specifically refers to a shift of perspective through time. He explains "[a]bout four years ago, HBO began to film a documentary about my family and me called *Life According to Sam*. That was a pretty great experience, but it

was also four years ago. And, like anyone my views on many things have changed, and hopefully matured” (09:36-9:50). In this moment, Berns speaks about his career choices, but this statement can also be read as a more general disclaimer for anything he may say in his TED talk that comes across differently within the documentary: His character has evolved; he sees things differently than four years ago. With these intertextual references he also points to the question of perspective: He says that some of his opinions on life have changed since he is now seventeen. Thus, the way life in general and age(ing) in particular are regarded is also always influenced by the life stage we are currently in. Berns hence confirms Gullette’s claim that a life narrative is always dependent on the moment it was written in. In other words: The same story, told by the same person may differ if it is told four years apart. Crucially, Berns uses the term matured which is often connected to a person’s behavior. What he describes in this instance is a change of perspective or attitude with increasing behavioral age. He implies that his perspective now should be given more merit, as his behavioral age has increased, and maturity has historically been tied to agency (cf. Field).

In conclusion, Berns does not use the increased agency he gains through his TED talk, to commodify himself or his condition but his attitude towards life which presents a significant difference to the documentary. However, many of the things Berns points to in his TED talk are also present within the documentary. Some of them may be framed slightly different, like the marching band storyline, while others are very much the same, as for instance the conclusion that Berns is not defined by his condition. However, it is also very clear that the focus of the documentary is a rather different one. Here, the interests of the PRF and HBO seem much more prevalent than in Berns’ own narrative. Ultimately, the documentary’s title is then somewhat deceptive as it claims to portray what life is like according to Sam Berns. Rather, it portrays what life with progeria is like according to the PRF, as well as how this life is best marketed for an HBO audience.

7.5 Framing Extraordinary Age(ing) in *Life According to Sam*

Using the HBO documentary *Life According to Sam* as a case in point, this chapter has shown how progeria as an extraordinary form of aging can contribute to the discussion of age as a cultural imaginary, the social roles tied to it, as well as the influence of the biological aspects of the aging process. As Sam Berns’ condition puts him between being ‘old’ and being ‘young’ by juxtaposing physical and behavioral age, his story shows how age itself is a fluid construct that is constantly redefined through the environments it is situated in. Ultimately, it is Berns’ behavioral age, made possible through supporters who are willing to work against the constraints in his environment, which determines how he is perceived and perceives himself

through his age. The situations in which his body and his physical age are the center of attention are restricted to the hospital, where he is isolated and fragile which leads to an understanding of the aging body as a challenge—which it undoubtedly is for everybody experiencing it—but one that does not have to be the defining aspect of a person's life.

Berns does not 'act his (physical) age' (cf. Laz) in his philosophy, thereby undermining the social emphasis that is put on this very aspect of the aging process. However, looking at his narrative also shows that the most arbitrary subcategory of age—institutionalized age—has a lot of power over the way age in general is determined, as it overwrites cultural imaginaries of the aging body. Thus, Sam Berns is not seen as an 'old' person even though the documentary constantly points to his physical age. Ultimately, the narrative remains an illness narrative, as well as a coming-of-age narrative, rather than one of 'old' age in any sense.

Progeria, and Sam Berns at the same time, are then commodified through otherness *and* sameness. The complex structures that this narrative is set in depict progeria as a communal disease, emphasizing a common aim not only for children with progeria but for everyone. It thus echoes claims of disability studies scholars to move away from depicting disability as an individual experience. At the same time, Berns is portrayed as an average U.S. American teenager and his story becomes an archetypical U.S. American story of success. Thereby, he is not only part of the progeria community but also of the (trans)national community in general. Especially his TED talk points to the sameness of his life and his alignment to a social norm. Interestingly, there is also a sense of the ordinary within Sam Berns' narrative, not only communicating his belonging within society but also a universality of the condition or illness as a whole. Illness, according to this narrative, can happen to anyone and is therefore specifically not an individual but a communal issue.