

EDUCATIONAL DISCUSSION GUIDE LIFE ACCORDING TO SAM

Released in fall of 2013, shortlisted for an Academy Award, and winner of a 2014 Peabody Award, HBO Documentary Film's LIFE ACCORDING TO SAM tells the story of Sam Berns, a remarkable young man excelling as a student, a percussionist in his high school marching band, an Eagle Scout, and more. Sam is a friend to many, a lover of music, and part of a close family. He's also living with a rare, fatal genetic condition called Progeria. All children with Progeria die of heart disease at an average age of 13 years. The film begins with Sam at age 13. He's in a race against time.

In the 90-minute film, we learn the story of Sam's diagnosis at age 2, how it affected his family, and how his physician parents began a quest to find a cure. As Sam grows older – and his body ages at an accelerated rate – we watch as his family launches and grows The Progeria Research Foundation, isolates the gene that causes Progeria and brings children from all over the world to Boston to take part in the first ever clinical drug trial testing a potential treatment for this fatal disease. It's a story of bravery, of determination, of hope, of scientific progress and of the love between parent and child.

Inspiring and heartwarming, LIFE ACCORDING TO SAM is also a powerful tool for engaging students in learning. The film sheds light on the biology of disease, the painstaking process of testing treatments for diseases, and it provides lessons on how science can be applied to help people live healthier lives. It similarly showcases how determination can fuel creative problem solving. In the film we see Sam's mother – PRF's lead researcher – face obstacle after obstacle. How she navigates these challenges isn't just inspirational, but educational for students learning how to face adversity.

The documentary also offers lessons in inclusion and interpersonal relationships. Despite his challenges, Sam lived his life as a regular teenager, and his friends and peers accepted him that way. He states at the very beginning of the movie that Progeria does not define him, and he sets the tone for dynamic discussion of this topic.

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At The Progeria Research Foundation, we are working every day to find the cure for Progeria and its aging-related disorders. We will accomplish that goal through research and education, expanding awareness of the condition and how research into a cure will not only help kids with Progeria, but also provide us all with a better understanding of the aging process and heart disease. LIFE ACCORDING TO SAM has helped quite a bit in this regard, introducing the facts behind Progeria – and the story of our organization – to millions around the world. We now seek to expand the awareness to students, in the classroom setting.

In screening the film, we urge you to use the questions below to generate dialogue about the important issues it explores. We created the questions specifically for student audiences, but as an educator, you will need to determine which questions will be most appropriate/most helpful for your students. You can expand your conversation by inviting a local scientist or university professor with experience in genetics or other related fields. If you have questions on how to best prepare for your screening and conversation, please feel free to contact us at info@progeriaresearch.org.

We also suggest your students watch Sam's 12-minute popular TedX talk, *My Philosophy for a Happy Life*, at https://www.youtube.com/watch?v=36m1o-tM05g. Over four million people have watched and been tremendously affected by Sam's talk, and we think your students will gain a lot from it as well.

Sample discussion questions

Science and Technology

- What struck you most about the biology of Progeria?
- What did you learn about the process for developing and testing drugs?
- What do you think about the long and detailed process required before a drug can be approved by regulators? Is it important that the process is so strenuous? Why? Would you make any changes to the process?
- Progeria is caused by a very rare genetic mutation. What constitutes a rare disease?
 What are some other genetic diseases? How and why do these mutations happen?
- As you can see in the documentary, a lot of research goes into making sure new drugs are safe and effective, which can make drugs very expensive especially for rare conditions like Progeria, where only a few hundred would need them. What could we be doing to make this process more affordable?

Problem Solving

- For over 100 years, researchers failed to prioritize Progeria because so few children were diagnosed with the disease. What do you think about that? How should society deal with challenges like this?
- Sam's mother was confronted with multiple roadblocks in the film. What were some of those and what can we learn from how she handled them?
- Did you think about some of your own challenges when watching the film? Are there ways you might apply some of what you learned in addressing roadblocks in your own life?



Empathy and Relationships

- There are many feelings this film can bring out. What are they and why do you think this is true?" Other than Sam, which characters had the greatest impression on you? Why?
- Do you look at your own life differently after watching the movie? Your own relationships? In what way?
- Despite his appearance and his health condition, Sam "fit in" just like any other kid in his school. He never experienced bullying within his community. Why doesn't that happen all the time when other students bring their own differences? How do you interact with others who are "different"? Will that now change, and why or why not?

Many thanks to the Foxboro, Massachusetts school administrators, and junior and high school teachers who contributed to this guide.

Opportunities for Service Learning

The Progeria Research Foundation began as a true "start-up." When Sam was first diagnosed with Progeria, his family put everything aside and launched this new organization, dedicated to finding a cure. Since that time, the organization has grown with the help and support of friends, neighbors, and an expanding list of donors and volunteers from around the world. Many of these supporters are students and children and, as with other service learning efforts, organizers often tell stories of how greatly the students grow from their experiences in learning, volunteering and otherwise playing a part in supporting such a critical cause.

LIFE ACCORDING TO SAM provides a unique opportunity to not only educate students around science and technology, problem solving, and empathy and relationships, but to also see the value in literally participating in PRF's journey toward a cure. In the past, kids have held events of all kinds – from bake sales to concerts – and created awareness-building campaigns, all to help PRF advance its mission to cure kids with Progeria.

We invite you to consider how your students can help build awareness and other support for PRF as you plan your next service learning project. Contact us to learn about what other students and educators have done, and how you can use the film as you teach the next generation about the value of service and helping other children their age.

To learn more, go to http://progeriaresearch.org/get_involved/ or contact us at 978-535-2594 or volunteers@progeriaresearch.org

