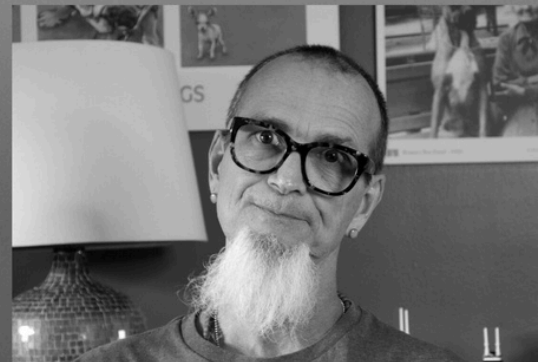


compromised.

[life without immunity]



DISCUSSION GUIDE

welcome.

[a letter from the director]

Nothing makes us think like a story. As a matter of fact, a good enough story can make us think an awful lot about topics we've never even considered before.

The most impactful tales ever told all have at least one thing in common, whether they be a Hollywood blockbuster, a song, an anecdote from a friend, ancient folklore, a Broadway play, or even a soap commercial.

They force us to question what we would do.

- Would I steal food if my child was starving?
- Am I as capable of forgiveness as that character?
- How would I react if I found out I was responsible for someone else's pain?

We knew that for this film to have the desired effect, we had to guide people toward thoughts much more abstract and unsettling than descriptions of neutrophils and immune panels.

From the earliest conversations I had with the featured cast of *Compromised*, I said that our goal was to "hold the audience's hand through a haunted house." Ben, Kim, Dionne, Victoria, Shane, and Jerry (and their families) have all experienced horrors they would never wish on anyone. Still, they were willing to sit with blazing lights in their eyes and a camera in their face to talk about unthinkable fear and pain in hopes that someone would feel a little less alone by hearing their story.

As you host your own screening and discussions, we encourage you to remember that this film is not strictly a medical documentary. It's a collection of stories about suffering, as well as the many, many unique ways the human spirit can overcome it to live joyfully and in full color. Almost no one has heard of primary immunodeficiency, but everyone can recognize the conflicting powers of struggle and hope. There's nothing more universal than that.

If we've done our jobs right, people will leave your screening of *Compromised* remembering the faces and voices and tears and laughter of people who live in a permanent, intimate war between struggle and hope. Who knows? They may even be inspired to help do something about it.

Zachary Moore

Zach Moore

Director, *COMPROMISED: LIFE WITHOUT IMMUNITY*

Digital media manager, Immune Deficiency Foundation



"I feel like it's hard to describe PI without mentioning the bad parts."

Ben, age 11

quick chats.

[talking points for short conversations]

As you prepare to engage in conversations following the film, remember that it may have been a turbulent emotional experience for some of your guests. You should encourage people to take a breath, have something to drink, and decompress if they need a moment to do so.

1. Have you ever heard of primary immunodeficiency before seeing this film? What do you think is the reason for that?
2. Which patient story resonated with you most? Why?
3. Did anything about the film surprise you?
4. Did anything about your own reaction to the film surprise you?
5. Is there anything you learned about in the film that you find yourself wanting to study even further?
6. Were there any PI symptoms mentioned in the film that surprised you?
7. What would you do to pass the time if you had to sit through a twelve-hour infusion like Ben does?
8. In the film, Dionne mentions that she's had an open wound for fifteen years. How might it affect someone's quality of life to have an open wound for that long?
9. Were you surprised that open wounds can be a symptom of a malfunctioning immune system?
10. Were you surprised by Victoria's decision to study medicine? Why or why not?
11. Shane's partner, Joan, made the decision to move his things into her house while he was hospitalized. What does that tell you about the types of decisions that must be made by loved ones of people with PI?
12. Jerry admitted that he has spent his entire life running from the attention his condition has brought his family. How would you feel if you received national attention for a disease you had?
13. What was the most interesting thing you learned from the medical professionals who appeared in the film?

deep dives.

[talking points for long conversations]

1. Think of the personalities of the people featured in the film (Ben, Kim, Dionne, Victoria, Shane, and Jerry). How might their respective conditions have shaped the way they think and see the world?
2. The film begins with a montage of news footage from the early days of the COVID-19 pandemic. Do you remember hearing or taking part in conversations about immunocompromised people during that time? Why do you think the filmmakers chose to highlight COVID so prominently?
3. Have you ever considered that a disease diagnosis can be a good thing? Have you ever considered that having a diagnosis removed could be a BAD thing?
4. It took Dionne four decades of pain, illness, and infection from the time of her first symptom to get a diagnosis and treatment. In your own life, what is an important moment you cherish that you may have missed if you were in her position?
5. Do you have a hobby that you love as much as Shane loves to garden? What would you do if your joy was a danger to you?
6. Do you think that further research on primary immunodeficiency could lead to advancements in OTHER fields of medicine? How so?
7. Kim speaks about the guilt of parenting a child with PI, especially knowing that Ben's condition was passed genetically from her. What would you say to a friend who was experiencing guilt like that?
8. Two types of immunoglobulin treatment are mentioned in the film (subcutaneous and intravenous). Can you remember the difference between the two? Which would you prefer to do if you had to take infusions?
9. Artificial intelligence is a very prominent and sometimes divisive topic in our society right now. Before seeing the film, how much had you ever considered its applications in medicine? How does it make you feel to know that so much progress has already been made in the field?
10. Reflect on what it must feel like to lose a sibling who gave you a second chance at life, as Jerry did. Likewise, think about the resilience his mother, Yvette, must have to endure such loss.



for the road.

[things to ponder for a while]

1. Why did the filmmakers use color and black and white in the way they did?
2. How might a greater public awareness of immune disorders make the world a better place for everyone, not just patients?
3. Near the end of the film, Dr. Vivian Hernandez-Trujillo guesses that she could see 10 more patients a week if she didn't have to spend time fighting with insurance companies. Consider what that could mean on a national or global scale.
4. 70-90% of people with PI have no diagnosis, nor any idea that they could need treatment. How could greater awareness reduce that number?
5. Think of the last time you spent time on the phone with your health insurer. How might a primary immunodeficiency amplify that frustration?
6. Dr. Stacey Clardy mentions that, in her research, they've found that CVID patients sometimes have more neurologic symptoms than traditional neurology patients. How might neurologic symptoms like fatigue, migraines, dizziness, etc. make it even more difficult to find a diagnosis and treatment?



Reflect as a group on how some of the following concepts affect people with PI differently. Do any of the phrases make you think of a specific person in the film?

acceptance

pain

innocence

grief

guilt

determination

longing

hope

dignity

quick facts.

[about the Immune Deficiency Foundation & primary immunodeficiency]

What is PI?

Primary immunodeficiencies (PIs) are a group of more than 450 rare, chronic conditions where a part of the body's immune system is missing or does not function correctly.

All primary immunodeficiencies are different, but they all disrupt the body's immune system. They are also known as inborn errors of immunity (IEI).



Who is the Immune Deficiency Foundation?

Whether you've been recently diagnosed, have been living with a primary immunodeficiency (PI) for years, or just think you might have a PI, we are here to help. While PI has no cure, there are lifesaving treatments available that can improve your quality of life. Our programs are meant to connect, engage, and empower families to live longer, stronger, healthier lives.

MISSION:

The Immune Deficiency Foundation improves the diagnosis, treatment, and quality of life for every person affected by primary immunodeficiency. We foster a community that is connected, engaged, and empowered through advocacy, education, and research.

VISION:

A healthier day, every day, for every person with immune deficiency.

Learn more at www.primaryimmune.org.



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