

# **ABOUT THE FILM**

STUMPED tells the story of filmmaker and professor, Will Lautzenheiser, who suddenly becomes a quadruple amputee due to a life-threatening bacterial infection. With the support of his loved ones and a world-class medical team, Will pursues stand-up comedy as therapy, and risks his life by undergoing experimental arm transplants in the hope of reclaiming his independence.

Within this medical drama, is a deeply personal story about resilience, committed caregiving, ethics, and the life-changing potential of pioneering medicine.

Running Time: 72 minutes
 Country of Origin: USA

Language: EnglishRating: Not Rated

Audience: High School and Above

# **SCREENING PARTNERS**

STUMPED can be used for education, community engagement and outreach with a variety of partners:

Colleges & Universities:
Medical, Nursing, Physical & Occupational Therapy
and Social Work Programs

Community & Student Groups
Disability Organizations

High Schools

Hospitals

Libraries

**LGBTQ Organizations** 

Museums

**Organ Procurement Organizations** 

Support Groups: Amputee, Caregiving, Rehabilitation and Transplantation

## **KEY THEMES**

STEM, Medicine and Health
Pushing Boundaries
Human Rights and Social Justice
Disability, Identity and Representation
Caregiving and Relationships
Organ Donation and Transplantation
LGBTQ Communities
Ethics

# PRODUCTION TEAM

**Director/Producer**Robin Berghaus

#### **Producers**

Bryan W. Davies Sam Kauffmann Kevin McCarthy

# **DISCUSSION QUESTIONS**

### Media Literacy: Story, Structure and Aesthetics

- 1. After watching the film, what was your response? Which moments did you consider to be compelling and memorable? Why?
- 2. If you had to summarize the film, what would you say it is about? What kinds of ideas and values are presented?
- 3. How was the story constructed? What did you see? What did you hear?
- 4. What visual devices are used to convey Will's physical challenges?

  Describe where the camera is placed, and how the images make you feel?
- 5. What motivated the creation of this film? Do you think the purpose was achieved?
- 6. Who is the target audience? How did the film make you feel? How do you think it made others feel?

#### Medicine, Health and Science

- 1. What type of support networks does Will need as he goes through arm transplantation?
- 2. How would you describe the personal and professional characteristics of Will's surgeons, and physical and occupational therapists? Which do you identify as important characteristics?
- 3. How do Will and his medical team work together?

  How would you describe their patient/health care provider relationships?
- 4. How are Will's experiences with medical care the same or different from experiences you have had?
- 5. If you could show this film to patients and their families, what are the most important insights you would want them to gain?

### **Pushing the Boundaries of Medicine and Health**

- 1. Should society invest time and money to improve human health and offer new medical treatments? Why or why not?
- 2. How might it be in our human nature to want to further explore medicine and health?
- 3. What does it mean to be a pioneer as a patient, scientist and health care provider?
- 4. What steps should scientists and medical teams take to safely push boundaries?
- 5. Identify scientists and health care providers who you have heard about. Why do you believe they are well known?
- 6. Has this film changed your perspective about the path through which medicine advances? Why or why not?

#### **Ethics**

- 1. If you were Will, would you take on the risks of experimental transplantation, even if it meant cutting your life short? Why or why not?
- 2. How do Angel and Will respond differently to the idea of risk-taking?
- 3. What is the price of pioneering a medical field? How much risk is too much? Is there a level of danger or risk that is too great?
- 4. How should a country spend its money on health care for its population? Do you think face and arm transplants should be covered by health insurance? Would you take \$1M and spend it on vaccines or a single experimental procedure?
- 5. If Affordable Care Act provisions that currently protect people with pre-existing medical conditions are no longer defended, transplant recipients and living donors in the U.S. could potentially be denied health insurance coverage.

What do you think about that possibility? How should the government, medical institutions and society respond?

### **Organ Donation and Transplantation**

- 1. How much did you know about organ donation and transplantation before the film? What did you learn?
- 2. How do think face and arm transplants impact the lives of the people who receive them?
- 3. Throughout the world, demand for organs far exceeds supply. According to the United Network for Organ Sharing (UNOS), more than 115,000 people in the U.S. need life-saving transplants, and approximately 20 people die each day while waiting (1).

How would you propose increasing organ donation rates in the U.S.?

European countries with the highest organ donation rates—Spain, Portugal and Belgium—have long standing "opt-out" systems in which all citizens are automatically registered as organ donors unless they chose to state otherwise (2).

Do you think countries, such as the U.S., that do not have opt-out systems and presumed consent laws, should consider adopting them to advance organ availability and transplantation?

What do you identify as the pros and cons of an opt-out system?

Do you think an opt-out system would be accepted in your country? Why or why not?

4. The world's first successful human organ transplant was performed in the U.S. in 1954. In contrast, Ethiopia performed its nation's first kidney transplant in 2015 (3).

What type of infrastructure is needed to perform organ transplants? What challenges do you think Ethiopia faced in preparing to perform transplants?

5. Throughout the world, low organ donation rates are attributed to several factors. In Germany, there was a scandal involving falsified patient information that caused a sharp drop (4). Where poverty exists, (5) and demand for organs has outstripped supply (6), an underground market and organ trafficking have instilled fear. In some countries people believe that Islam prohibits donation (7), even though fatwas (legal opinions) exist that permit organ transplantation when carried out freely to help people (8).

How would you address these issues? How would you work toward rebuilding public trust?

How would you collaborate with diverse cultural and religious communities to support their needs, and to educate about organ donation and transplantation?

### Disability, Representation and Identity

- 1. How do you define "disability," and what is your experience with this word?
- 2. How could stereotypes affect your interactions with people with disabilities?
- 3. Did this film cause you to view disability in a different light?
- 4. How is Will represented as a person with a disability?
- 5. Describe Will's use of humor.
  Why do you think he pursues stand-up comedy?
- 6. How do Will's disabilities affect his relationships with his loved ones?
- 7. How do you think Will's identity changed as he transitioned from filmmaker, to quadrilateral amputee, to arm transplant recipient?
- 8. If you were experiencing illness, do you think you would remain private or choose to share your experiences as Will did?
- 9. How does your ability to move around influence your activities and the places you go? What changes could communities make that would expand options for people with disabilities?
- 10. What routines do you perform that require careful planning for people with severe disabilities?
- 11. If you have experienced major illness or injury, what advice did you receive? Did it help you? If so, how?

### **Caregiving and Relationships**

- 1. How do Will's disabilities affect his loved ones?
- 2. How is Angel represented as Will's partner and caregiver?
- 3. What kind of sacrifices does Angel make as Will's caregiver? What challenges does Angel face? What do you imagine might have been going on in Angel's mind? If you were in Angel's position, what would you do? How would you feel?
- 4. How might Will's life have been different if he hadn't received Angel's support? What motivates people to give selflessly to others?
- 5. How do you perceive the role and value of caregiving?
  Are caregivers valued and supported by society? If so, how?
  Does society have a moral obligation to support caregivers? Why or why not?
- 6. What lifestyle changes come with severe disability?
  How can a family prepare emotionally and practically to respond to these changes?
  What can friends and the community do to help them prepare?
  What resources exist in your community?
- 7. Are there obstacles caregivers could face that might prevent them from asking for help? Describe the obstacles and what could be done to help them overcome those barriers.
- 8. How can friends who are not primary caregivers best support their loved ones with disabilities?
- 9. Will has resources, including health insurance and loved ones who help as caregivers.

How does society provide for people who don't have those resources? What structures should be developed?

- 10. What are the legal and financial issues that a person with a severe disability and his or her family must face?
- 11. Should health care providers offer support to caregivers and families? If so, when and how?

#### **LGBTQ Communities**

- Before viewing this film, what did you know about people from LGBTQ communities?
   What were the sources of your ideas?
   Has this film influenced your view? Why or why not?
- 2. How do you think LGBTQ patients experience the health care system?
- 3. How can health care providers support their LGBTQ patients?

### **Concluding Questions**

- 1. Describe what you learned from this film that you wish other people knew. Could that knowledge help to make an impact on society? If so, how?
- 2. Who would you recommend watch this film? What do you hope they would learn?
- 3. Have you been inspired by this film or discussion? If so, how?

#### References

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# **IDEAS FOR CHANGE**

### **Human Rights**

Investigate the current status of health care in your state, and the civil rights and legal protections for Disability and LGBTQ communities. Tell your elected representatives where you stand on the issues.

### **Organ Donation**

Invite an Organ Procurement Organization to your event to speak about organ donation and transplantation. Help register community members who want to become organ donors.

Find your Local Organ Procurement Organization: https://www.organdonor.gov/awareness/organizations/local-opo.html

# ABOUT THE DIRECTOR

Robin Berghaus has directed, produced, filmed and edited more than 100 short documentaries, commercials, and educational videos. STUMPED is her debut feature documentary. Robin is a recipient of grants from LEF Foundation, Austin Film Society, Frameline and Women in Film Dallas. Her work has won multiple awards, and has been exhibited internationally, including at the British Film Institute, Palm Springs International Film Festival, and as part of Alfred P. Sloan Foundation's Science on Screen.

Robin is a keynote speaker, distinguished lecturer, panelist and juror for film festivals, universities, high schools and organizations. She serves as a film envoy for American Film Showcase, a cultural diplomacy program produced by the USC School of Cinematic Arts, U.S. Department of State and U.S. embassies and consulates worldwide.

Robin has an interdisciplinary background in science and film. She earned a B.A. in biology from Boston College, and a M.F.A. in film production from Boston University.

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