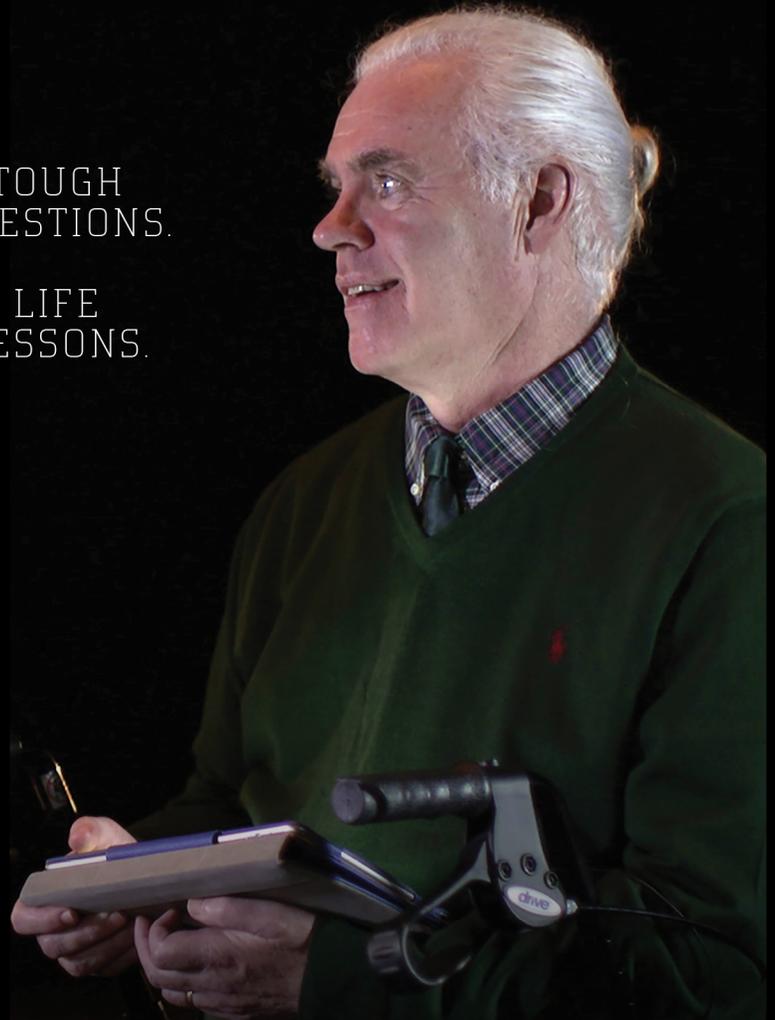




TOUGH  
QUESTIONS.

LIFE  
LESSONS.



**BROADCAST PREMIERE**  
on **WORLD Channel's**  
*Local, USA* starting  
**June 11, 2018**  
*(check local listings)*

# MR. CONNOLLY Has ALS

FILMED, DIRECTED AND PRODUCED BY DAN HABIB FILM EDITOR DIEGO SIRAGNA STORY EDITOR JODY BECKER STORY CONSULTANT SAMUEL HABIB  
FEATURING GENE CONNOLLY, PATTY CONNOLLY, SAMUEL HABIB AND THE STUDENTS OF CONCORD HIGH SCHOOL MUSIC BY PHOENIX AND THE BEACH BOYS  
PRODUCED BY D.H.PHOTOGRAPHY, LLC IN COLLABORATION WITH THE INSTITUTE ON DISABILITY AT THE UNIVERSITY OF NEW HAMPSHIRE



[facebook.com/MrConnollyHasALS](https://www.facebook.com/MrConnollyHasALS)



[@\\_danhabib](https://twitter.com/_danhabib)

Community Engagement Toolkit





# About the Film



For 14 years, Concord High School Principal Gene Connolly was always on the go. Whether in the press box at football games or greeting students at the start of every school day, he was an active, engaged leader who left a profound impression on the thousands of young people he guided during his 35 years as an educator.

Then, in 2014, the gregarious Connolly received news that would change the trajectory of his career and life forever. He was diagnosed with Amyotrophic Lateral Sclerosis (ALS), a neurological disease that attacks the nerve cells and leads to progressive muscle weakness and paralysis. He joined approximately 20,000 other Americans living with ALS, which typically results in death within 2-5 years.

Since the onset of his illness, Connolly showed tremendous persistence, humor, and leadership in the face of this degenerative, fatal disease. Connolly credits the school and the greater Concord community as a source of unfailing support and understanding as his illness progressed, allowing him to continue to lead the school for two years while also raising awareness about the disease locally, statewide, and nationally.

Connolly retired in June 2016, but the strength, positivity, and honesty that he demonstrated as he lost the ability to walk and speak will be his most profound legacy, particularly for the students who were part of his journey. Award-winning filmmaker and Concord High School parent, Dan Habib, has captured Connolly's legacy in

this 32-minute documentary film. Habib engaged the entire student body in a video interview process. Students submitted more than a 1,000 questions (which were narrowed down to 50) that examined themes such as how to live life fully; develop resilience; show love freely; identify priorities; what it feels like to acquire a disability; how people perceive individuals with disabilities; and how to approach an inevitable death with honesty and dignity.

As Connolly says in an interview for the film, his ALS has taught him a deeper understanding of what it means to be disabled. "While I look different, inside I am the same person," he said. "It can be frustrating and exhausting. I have a newfound respect for people with disabilities."

# What is ALS?

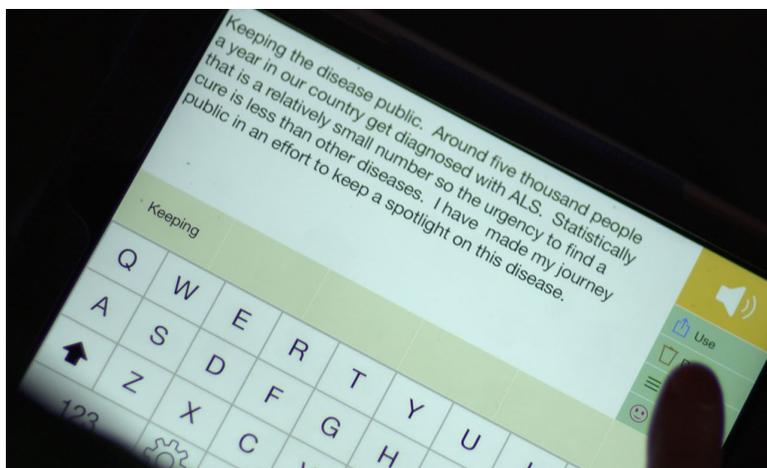
Courtesy of the ALS Association  
From:

[ALSA.ORG/ABOUT-ALS](https://www.alsa.org/about-als)

ALS, or Amyotrophic Lateral Sclerosis, is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. A-myo-trophic comes from the Greek language.

“A” means no. “Myo” refers to muscle, and “Trophic” means nourishment – “No muscle nourishment.” When a muscle has no nourishment, it “atrophies” or wastes away. “Lateral” identifies the areas in a person’s spinal cord where portions of the nerve cells that signal and control the muscles are located. As this area degenerates, it leads to scarring or hardening (“sclerosis”) in the region.

Motor neurons reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. The progressive degeneration of the motor neurons in ALS eventually leads to their demise. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With voluntary muscle action



progressively affected, people may lose the ability to speak, eat, move, and breathe. The motor nerves that are affected when you have ALS are the motor neurons that provide voluntary movements and muscle control. Examples of voluntary movements are making the effort to reach for a smart phone or step off a curb. These actions are controlled by the muscles in the arms and legs.

There are two different types of ALS, sporadic and familial. Sporadic, which is the most common form of the disease in the U.S., accounts for 90 to 95 percent of all cases. It may affect anyone, anywhere. Familial ALS (FALS) accounts for 5 to 10 percent of all cases in the U.S. Familial ALS means the disease is inherited. In those families, there is a 50 percent chance each offspring will inherit the gene

mutation and may develop the disease. French neurologist Jean-Martin Charcot discovered the disease in 1869.

Recent years have brought a wealth of new scientific understanding regarding the physiology of this disease. There is currently one FDA-approved drug, Riluzole, that modestly slows the progression of ALS in some people. Although there is not yet a cure or treatment that halts or reverses ALS, scientists have made significant progress in learning more about this disease. In addition, people with ALS may experience a better quality of life in living with the disease by participating in support groups and attending an ALS Association Certified Treatment Center of Excellence or a Recognized Treatment Center.

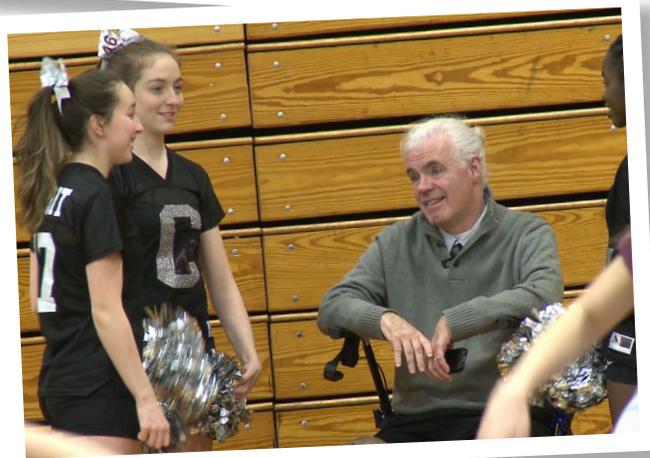
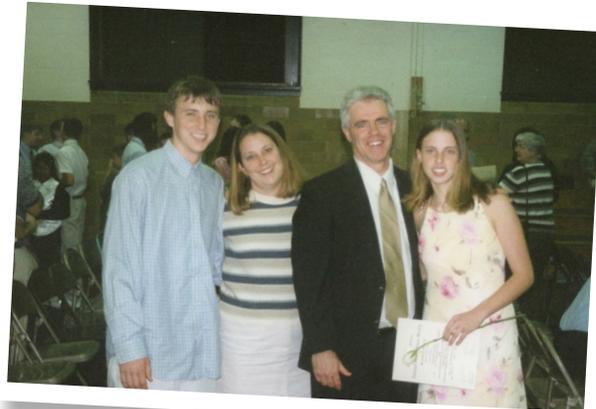
## What is ALS? (continued)

ALS usually strikes people between the ages of 40 and 70, and it is estimated that there are more than 20,000 Americans who have the disease at any given time (although this number fluctuates). For unknown reasons, military veterans are approximately twice as likely to be diagnosed with the disease as the general public.

Notable individuals who have been diagnosed with ALS include baseball great Lou Gehrig, theoretical physicist, cosmologist, and author Stephen Hawking, Hall of Fame pitcher Jim “Catfish” Hunter, Toto bassist Mike Porcaro, Senator Jacob Javits, and actor David Niven, among many others.

To find a Center near you, visit:

**ALSA.ORG/COMMUNITY**



# Discussion Questions

## 1. Communicating Difference and Disability

**“As my ALS symptoms have become more pronounced, I have noticed when people approach me they speak with me differently. They think the disease has affected my cognitive abilities. It can be frustrating and exhausting. I have a newfound respect for people with disabilities.”**

— Mr. Connolly



People with disabilities have historically been denied access to ordinary spaces, experiences, and relationships. Barriers such as segregated classes or schools, lack of representation in the media, and misconceptions about disability maintain stigmas and disrespect. For example, in the film, the filmmaker shares that his teenage son Samuel, who lives with Cerebral Palsy, is often spoken to as if he is a toddler—a painful and frustrating misinterpretation of Samuel’s disability. Mr. Connolly relates to this experience as his ALS progresses and he loses the ability speak.

Mr. Connolly invites students into a frank dialogue, offering them

a unique learning opportunity and challenging the notion of disability or difference as “not normal.”

### Discussion Questions:

Taking Mr. Connolly’s lead, openly explore societal and personal perceptions of disability and difference.

1. Do you see people who are nervous or unsure about how to communicate with someone with a disability? Why do you think they are nervous? Do you sometimes feel that way?
2. How and where are people with disabilities represented in the media?
3. What are the common conceptions or misconceptions surrounding disability?
4. What are some of the fears, discomforts, or unanswered questions that people have about disability?
5. If you have a close friend or family member with a disability, how has that affected your perception of other people with disabilities?
6. How does Mr. Connolly’s experience with ALS impact how he contributes to inclusion in his school and community?

# Discussion Questions (continued)

## 2. The Importance of Belonging

**“When I was in high school and college, it was the height of un-coolness to tell someone that you love them. Well, I am going to give you permission to break the rule. The new rule is if you love someone, you have to tell them.”**

— Mr. Connolly

Mr. Connolly is celebrated for creating an environment of inclusivity and belonging. Concord High School values the richness of diversity. A few examples highlighted in the film include welcoming immigrants and refugees, becoming the first high school to elect a transgender student as homecoming king, and hosting a sports team of players with blended abilities. Each student is seen and supported as an individual with gifts and unique contributions. Difference is celebrated as a necessary

component of a healthy school community.

Mr. Connolly urges students to bypass “cool” in order to show love freely, a vulnerable act that can unite powerfully across lines of identity.

### Discussion Questions:

1. What does it mean to belong to—versus exist in—a community?
2. What might be the emotional

and physical consequences of not belonging?

3. How does a strength-based approach (in other words, looking for the talents in every person) support a diverse community of belonging?
4. How does vulnerability deepen relationships?
5. What does inclusion look like? How and what does Mr. Connolly contribute to inclusivity?

## 3. (Re)creating a Life of Purpose

**“Life is not for the faint of heart. It can be cruel and unfair. Living a fulfilling life can be challenging. Our job is to live our lives with purpose.”**

— Mr. Connolly

Known for his non-stop energy, Mr. Connolly’s life purpose was connected to his ability to be consistently present, involved, and active with a school community of over 1,600 students. Life significantly changed when Mr. Connolly was diagnosed with ALS: His

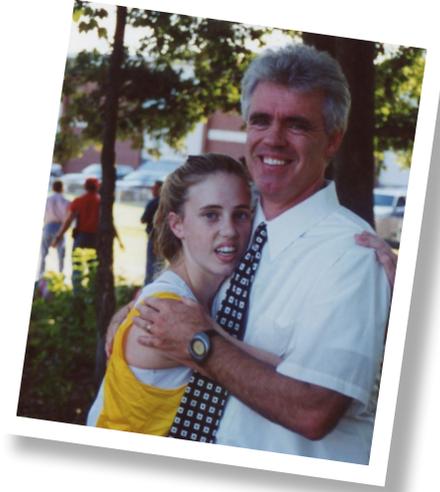
communication slowed; the ALS compromised every physical activity and passion, such as playing guitar, running, and traveling with his family; and his reliance on family, friends, and paid support increased. The ALS disrupted Mr. Connolly’s every future goal and plan.

This change also opened up and required a new perspective and purpose, amplifying his commitment to living in the present, becoming more intentional in communication, and taking up a new and important cause—advocating for a cure for ALS.

# Discussion Questions (continued)

## Discussion questions:

1. What are some other ways that ALS actually opened up new growth opportunities for Mr. Connolly?
2. What ingredients and elements support a life of purpose and contribution?
3. What effects, both negative and positive, happen when life changes without warning, interrupting our charted path?
4. How did Mr. Connolly's perspective help him to maintain his sense of life purpose in the face of unexpected life challenges?
5. What lessons can be learned from his journey?



# Group Activities



## 1. Challenging Assumptions and Perceptions

**Purpose:** In the film, students were given the opportunity to ask their principal, Mr. Connolly, questions about his experience living with ALS. The students were able to approach him with a spirit of open inquiry, which in turn allowed Mr. Connolly to inform them of his individual experience. This activity invites participants to challenge assumptions and reclaim identity.

What kind of snap assumptions were made—and how? What clues did the participants rely on under pressure?

Invite participants to share a time, by writing or in pairs, that they were typecast or stereotyped or had an incorrect assumption made about them. Offer questions to deepen the sharing: Why do you think this assumption was made? How did it feel? Did you correct the person? Why or why not? What was the truth about you that was not witnessed? Synthesizing the experience to a single statement, ask participants to fill in the blanks:

They thought I was \_\_\_\_\_.  
Instead, I am \_\_\_\_\_.

Read the statements out loud in a circle. Offer participants the opportunity to share the details of their story to the larger group and process the act of reclaiming personal identity.

**Modify:** Modify this activity to become an individual exercise by using the prompts to journal or free write.

**Activity:** Invite participants to write, draw, or identify in any way a piece of clothing or accessory that connects to their identity on an index card. They should do this privately, without showing it to anyone else at first. This can be a piece they wear often or only on special occasions. Some examples might include traditional or cultural attire, a necklace with religious iconography, a hoodie, headphones, glasses, etc.

Pick up the index cards and shuffle them until they are completely anonymous. Hand back the cards at random. Give two minutes for the participants to match the accessory/clothing to the person to which they believe it to belong. Return to the larger group setting. Discuss the process. Were the guesses right?



# Group Activities (continued)



## 2. Building Environments of Radical Inclusion

**Purpose:** When organizing events and group activities, the inclusion of people who move, hear, see, think, or speak in non-typical ways is often an afterthought. This activity aims to reshape how we create group experiences by building the consideration of all potential participants into the planning process and brainstorming ways to welcome the diversity of identities and abilities that exist among us.

**Activity:** For this exercise, identify a fun activity or event as a group. You might choose a sports event, an art day, a talent show, a debate team, etc. Begin by brainstorming the creative aspects of the planning process, envisioning where the event will take place, what will happen during the event, how people will be notified and/or invited to attend, media coverage that might occur surrounding the event, etc.

When the brainstorm is finished, pause to consider the experience of a person unable to access all

or a portion of the activity. What would it feel like to arrive at an event and be unable to fully participate? What message does this send to the participant? How might this experience affect a potential participant's desire to join a group or to try a new activity?

Introduce the concept of equity vs. equality—two systems that promote the concept of fairness. Equality means treating everyone the same; it assumes that a diverse group of people begins at the same level and experiences the same needs. Equity considers the specific needs of the individual and what they require to succeed. Take a moment to consider the relationship of equality and equity to differences such as disability, socioeconomic status, ethnicity, citizenship status, sexual orientation, etc.

On chart paper, brainstorm the elements necessary to ensure equitable participation for individuals with various differences at your activity or

event, relating to:

- The venue or site
- Transportation to and from
- Communication during
- Types of refreshments served
- Access to activities
- Advertising
- Preparing for media coverage
- The overall budget

Reflect on the process. Did considering the wide diversity of participants make the planning process more difficult? Did you experience any aha moments? How can you carry this experience into your everyday life?

**Modify:** Modify this activity to become an individual exercise by using the prompts to journal or free write.

# Group Activities (continued)

## 3. Defining a Life of Purpose

**Purpose:** Watching Mr. Connolly live life with vigor, strength, humor, and passion underscores the importance of life purpose. This activity guides participants in a process to identify the elements that generate purpose in one's life.

**Activity:** Interview a friend, family member, peer, or colleague on their concept of and journey toward a purposeful life. Prepare for the interview with a list of open-ended questions. Consider asking questions that touch on both a) external motivations, which rely on rewards, demands, or obligations to propel the achievement of a goal, and b) internal motivations, which draw on a sense of personal satisfaction or accomplishment. Personalize and ask follow-up questions, but refrain from inserting your own experiences during the interview. Even if recording, you may also want to take notes—a task that can be helpful when practicing engaged listening.

Some questions to kick start your process might include:

- What activities did you love to do as a child?
- In what ways are you afraid to embarrass yourself?
- What social issues fire you up?
- Who inspires you (people in your life, famous role models, etc.)?
- What could you easily and passionately teach someone else to do?
- If you were on stage and could say anything to a large audience, what would your message be?
- What adversity and hardship have you overcome? How did you do it?
- Is there a time you were doubted, but proved the person doubting you otherwise?
- What is a dream you have had and denied? Why have you denied it?
- What do other people tend to thank you for?
- Have you ever stood up for someone who was being excluded because they were different? Has anyone ever stood up for you? How did that feel?
- How best do you quiet the voice in your head that is constantly making assumptions and judgements about yourself or others?

Allow them to reverse the process, turning the questions back on you. Debrief on your experience together. What did you learn about each other and yourself? Were there shared experiences or philosophies? Did any epiphanies arise?

**Modify:** Modify this activity to become an individual exercise by using the prompts to journal or free write.

# Group Activities (continued)

## 4. Practicing Intentional Listening

**“Losing my ability to speak has forced me to be a better listener. Now I hear more than a person’s words. I have a greater sensitivity to a person’s tone, the nonverbal message that is every bit as important as the words.”**

— Mr. Connolly

**Purpose:** The act of listening can help us better understand people we are in relationships with, deepen our connections, and strengthen our capacity for empathy. When Mr. Connolly lost his ability to speak, his listening became more nuanced and conscious. This exercise invites participants to practice intentional listening and reflect on the process.

**Activity:** In pairs, invite participants to share a story about a challenging moment in their life. Only one participant can speak at a time. Participant B must listen and not interrupt Participant A while they are storytelling, and vice versa. Set a timer for five minutes.

Invite Participant A to begin their story. The facilitator should keep an eye on the timer. At approximately each two-minute mark, pause the storytellers and offer a prompt to consider. Participant B should take brief notes on their experience as it relates to the prompt. Invite Participant A to return to their story. When participants swap roles, use the following two interruptions.

### First Five Minutes of Storytelling:

Participant A — storyteller

Participant B — listener/note taker at prompts

- **Interruption One:** What is the purpose of your listening? Are you finding yourself wanting to give advice? To relate to the experience with an experience of your own? To argue a point or offer a fact?
- **Interruption Two:** Evaluation versus understanding. Do you find yourself judging or evaluating the content of the story? Are you rooting for the storyteller or the friend? Did the storyteller overreact? Is the storyteller not reacting enough?
- **Reflection:** When the five minutes is up, Participant B should reflect back what they heard. Ask Participant A if their story was captured correctly.

### Second Five Minutes of Storytelling:

Participant B — storyteller  
Participant A — listener/note taker at prompts

- **Interruption Three:** Body language. Notice your body language. Are you open and leaning in? Are you distancing

yourself? What about the storyteller? What are their facial expressions or gestures telling you in addition to their words?

- **Interruption Four:** Distraction. Do you find your mind chattering or wandering? Do thoughts of what to have for dinner or how much work you have to do slip in? What internal dialogue is taking place in your mind, even as you are listening?
- **Reflection:** When the five minutes are over, Participant A should reflect back what they heard. Ask Participant B if their story was captured correctly.

Debrief the experience as a group, sharing notes. What was difficult about listening? What was easy? Did it feel natural not to respond? Often our casual, conversational flow will not mirror intentional listening. What are the benefits of intentional listening? Are there specific times and places to use it as a tool? How might this exercise be modified for someone who doesn’t use their voice to express themselves or if English is not their primary language? Do you agree that 50 percent of communication is listening?

# Group Activities (continued)

## 5. Rewriting the Narrative

**“You will face adversity. Life is full of challenges. We get little say in what happens to us, but everything to say in how we deal with it. In fact, our responses will define us.”**

– Mr. Connolly

**Purpose:** Mr. Connolly models how to reshape negative experiences by choosing our responses to them. This activity uses creative writing to view a personal story through two different lenses, ultimately reframing the experience through narrative.

**Activity:** Invite participants to choose a story from their life that has been bothering them. Depending on their willingness to dive into vulnerable territory, they might choose a small incident that upset them or focus on a significant life change. The only requirement is that in the story, the writer is the person involved in the difficult circumstance.

Invite participants to follow these steps in rewriting their narrative:

1. Write down the event that occurred, as objectively and observationally as possible. Set it aside.

2. Gather images of weak/sensitive/breakable things. For example, the inside of a clam, a wine glass, a string unraveling, the soft spot on a baby’s head, brittle bones, the inside of an elbow, ice on a melting river, the stem of a flower, cotton being pulled apart, clouds, an old window pane, moth wings drawn to light, the legs of a spider, etc.
3. Gather images of strength and power. For example, lightning, a flood, an ancient tree, a lion’s jaw, a judge’s gavel, metal chains, weeds growing through fields, steel-toed boots, a hammer, a deep throbbing bass line, a nurse’s needle, a space ship, a whale, etc.
4. Examine your story describing the event. Imagine two possible endings for this story: one where you suffer (likely your current orientation to the story), and one where you soar. In each

version, utilize your images to weave into the piece. Feel free to mix and match the truth and fantasy, working with a flexible imagination, creativity, and an openness to mythology. The goal of documenting ending one (suffering) is to perform catharsis, or an emotional release. Ending two (soaring) offers another perspective, one that might encourage the individual to reframe the original experience. Documentation can take the form of collage, written word, music, pantomime, or any other creative form that appeals to the participant.



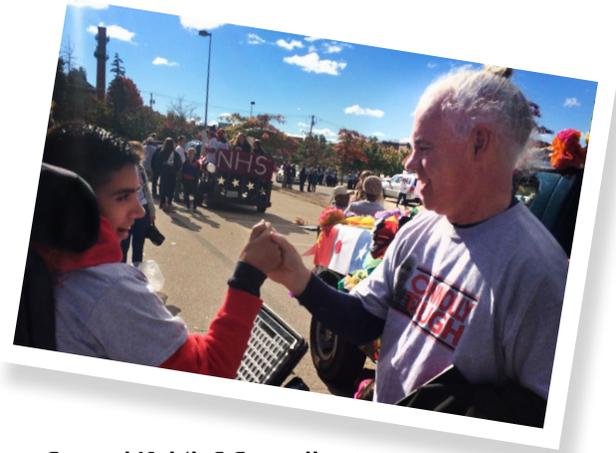
# Film Resources

## ONLINE

site: [MRCONNOLLYHASALS.ORG](http://MRCONNOLLYHASALS.ORG)

 [facebook.com/MrConnollyHasALS](https://facebook.com/MrConnollyHasALS)

 [@\\_danhabib](https://twitter.com/_danhabib)



Samuel Habib & Connolly at Homecoming (JPG)

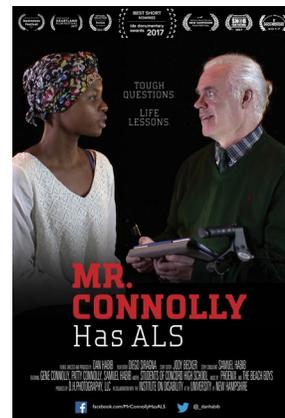
## ASSETS



Connolly with Seignee Mugisha (JPG)



Gene Connolly 2016 Graduation (JPG)



Film Poster (PDF)

## TRAILERS



Official Trailer



Extended Trailer

# Credits

## Written by:

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Steve Rothenberg

Mary Schuh

Susan Shapiro

The Connolly Family

The Rotary Club of Concord,  
NH

Institute on Disability/UCED



University of  
New Hampshire

impact  media

P A R T N E R S

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Learn how Mitsubishi Electric America Foundation is working to empower youth with disabilities at [meaf.org](http://meaf.org).



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