



## DISCUSSION GUIDE



TWISTED tells the stories of people who live with dystonia, a neurological disorder that forces your muscles to twist into abnormal, often painful, movements or postures. Pat Brogan, a basketball coach and triathlete who developed dystonia after a bike accident; Shari Tritt, whose dystonia affects her whole body, and Remy Campbell, an artist who gambled on a radical form of brain surgery—and won. Together, these individuals try to answer the question, when you are trapped inside your body, what will set you free?



## FROM THE FILMMAKER

Over 20 years ago, after seeing doctor after doctor and after years of living with a condition that defied explanation, I was finally diagnosed with Tourette Syndrome, a neurological disorder defined by multiple involuntary motor and vocal tics. Why did it take so long? Did people, including doctors, not know about Tourette Syndrome? As a filmmaker, I knew I was in a position to do something about this, so I made *Twitch and Shout*, a documentary about people with Tourette Syndrome, which aired on PBS. After that broadcast, Tourette Syndrome became a household word.

Many years later, I was *also* diagnosed with a form of dystonia, an even lesser known neurological disorder. They say 300,000 people in North America have some form of dystonia, but through my experience I know those statistics are low. Many doctors have never even heard of dystonia. Often, only the most tenacious get a diagnosis, seeing up to 80 doctors before the disorder is properly recognized!

After experiencing how a TV broadcast can reach millions and radically change the face of a disorder, I set out to make a film about people who live with dystonia. My hope was to make a film that would educate the public about dystonia and lead to more people getting diagnosed faster.

But my challenge was: how could I make a film about a specific neurological movement disorder that will interest the general public and that will be sexy enough to keep them engaged for a full hour?

Here is where I got lucky. At a dystonia conference, I found Shari and Ira Tritt. Shari who can't speak, as a result of a childhood brain surgery to treat her dystonia, and her husband Ira who is a self-proclaimed "loud mouth New Yorker." They met on the Internet, and their relationship transcends language. I also found Remy Campbell and Peter Cohen. They both had undergone a radical form of brain surgery called deep brain stimulation (DBS) that completely transformed the way dystonia impacts their lives.

I then decided to find someone who was considering doing DBS and follow them for a year. I was introduced to Pat Brogan, a basketball coach, who developed dystonia as a result of a bicycle accident. When I first met him in August 2004, he was contemplating whether to have the DBS surgery. After much deliberation with family, friends and doctors, he decided to go ahead with it, and we shot his entire operation (which lasted nine hours). In my naiveté, I fully expected his results to be as remarkable as those of Peter and Remy. After all, DBS worked magically for them. It was almost like science fiction! The film would have a happy ending.



That is when the trajectory of the film took a turn. Following the surgery, Pat's dystonia worsened. And instead of communicating with me, he would disappear and hide. I was trying to be respectful of his privacy, but how could I document his struggles without being intrusive. I decided to hand Pat's wife Cathy a video camera. She collected the most intimate footage of Pat on his journey—footage we never could have obtained in the presence of a film crew. She shot footage of him at his doctor's appointments and at basketball practice. Pat even took hold of the camera and filmed himself talking about his deep frustration and anguish with the unpredictable outcomes of the DBS.

The rollercoaster ride we all took with Pat was haunting and completely unexpected. It was painful to watch him get better only to go downhill again. We had no idea where the film was going to land. The films I made in the past were upbeat and what one might call "feel good" films. This film was becoming a tragedy... right up until the last month of shooting when things took yet another turn.

In the beginning, I set out to make a film that would shed light on a little known neurological disorder called dystonia. I also wanted to capture the transformations that take place as a result of the triumphs and travails of the human condition. In the end, TWISTED became a film about relationships, love, struggle and, ultimately, hope.

**Laurd Chiten**

## THE FILM

What would your life be like if you told your body to do one thing, but your brain told it to do something else, as if your brain had a mind of its own? Filmmaker Laurel Chiten and the people she profiles don't have to wonder about how to answer that question. They live with dystonia—a neurological disorder that causes muscles to twist into abnormal, often painful, movements or postures.

In *TWISTED*, Chiten's hour-long documentary, viewers learn about this often hidden disease through the eyes of dystonia sufferers. What emerges is a series of detailed portraits of people whose approach to their physical condition is shaped by their very different personalities and circumstances.

The film features the victories and frustrations of Pat Brogan, a basketball coach and triathlete who developed dystonia after a bike accident; the outgoing Shari Tritt, whose dystonia has affected her whole body since childhood; and Remy Campbell, an artist who gambled on a radical form of brain surgery—and won. Together, these individuals try to answer the question, when you are trapped inside your body, what will set you free?

*TWISTED* also challenges viewers to think about how our culture looks at disability and how people are affected by stereotyping. In addition, it raises issues related to medical ethics, mind/body connection, and access to health care, all of which make the film a powerful outreach tool.

### People Whose Stories are Featured in *TWISTED*

**Pat Brogan**, basketball coach and triathlete suffering from trauma-related dystonia

**Remy Campbell**, photographer and filmmaker whose general dystonia has been controlled by experimental brain surgery

**Laurel Chiten**, the filmmaker, who developed dystonia following a car accident

**Shari Tritt**, has had generalized dystonia since childhood, who now works in a retail store and has made a happy life with husband Ira

## BACKGROUND INFORMATION

Dystonia is a neurological disorder that causes uncontrollable, often painful, sustained muscle contractions that can cause twisting and repetitive movements or abnormal postures.

According to the Bachmann-Strauss Dystonia and Parkinson Foundation, 500,000 people in North America have some form of dystonia. The Dystonia Medical Research Foundation puts the number at 300,000

Dystonia can affect one or more parts of the body, including muscles in the face, neck, throat, eyelids, arms, legs, or torso.

There are different types of dystonia, usually classified by age of onset, parts of the body affected, and source of the onset (genetic, trauma, or medication). “Generalized dystonia” is used to describe the disease when it affects the whole body.

There is no cure for dystonia, but some experimental treatments have helped some people with the disease. These include botulinum toxin injections (which relax the muscles), and a neurosurgery procedure called Deep Brain Stimulation (DBS), during which a “pacemaker” is implanted in the brain.



## THINKING MORE DEEPLY

### General

- What did you learn from the experiences of the people featured in TWISTED?
- If you could ask any person in TWISTED a question, what would you ask and why?

### Medical Issues

- Before the viewing the film, what had you heard about dystonia? Why do some diseases seem to be more visible than others? What are the implications of visibility or the lack of visibility on research, treatment, and support for individuals and families dealing with a diagnosis?
- Several of the people in the film experience having doctors misdiagnose or discount their symptoms. What is your experience with doctors listening to you and/or taking you seriously? What might you do to increase the likelihood of accurate diagnoses in cases of dystonia?
- Discuss the ethics involved in promoting DBS (the brain surgery featured in the film). What are the pros and cons of treating dystonia sufferers with experimental procedures? What are the broader implications of treatment that allows a doctor to “program” a person's brain?
- If you were in Pat's position, what kinds of factors would go into your decision about whether or not to have brain surgery?
- What are the side effects of a disease like dystonia in terms of things like social networking, family life, work, and mental health? Given both the physical and non-physical impact, in what ways might family, friends, health care providers, and/or colleagues support people with dystonia? What could you do?

### Stereotyping

- Shari says, “I get angry when people misinterpret what I have. They think I am retarded.” What are the roots of the stereotype that people with physical disabilities are also mentally impaired? What could you do to counter those stereotypes?
- Remy says, “I just wanted to be tall. I just wanted to be straight. I just wanted to be normal.” Why is the desire to be normal so powerful? How does it influence your life? How do you define “normal”? What kinds of people fit into your definition? What kinds of people are excluded from it?

### Identity

- The filmmaker asks, “when you are locked inside your body, what can possibly set you free?” How would you answer?
- How much is your identity tied up with what your body is able to do physically? How might your self-image change if your body didn't have those capabilities?
- Do you notice gender-based differences in terms of how people deal with dystonia? In your view, do men and women relate to their bodies or their physical capabilities differently?
- Several of the film's participants met at conferences for people with dystonia. What is the power in meeting others who share at least some of your experience?
- At one point, Pat says, “hope is a dangerous word.” What do you think he means? What is the role of hope in coping with adversity?



## SUGGESTIONS FOR ACTION

Together with other audience members, brainstorm actions that you might take as an individual and that people might do as a group. If you need help getting started, you might begin your list with these suggestions:

- Investigate the types of support organizations that exist for people with disabilities in your community and commit to finding a way to help. If no organizations exist, start one.
- Hold an educational session on dystonia to help publicize the disease. You might also raise funds for research towards treatments and a cure.
- Organize a special screening of TWISTED for doctors, nurses, and other medical professionals in your community.

For additional outreach ideas, visit [itvs.org](http://itvs.org), the website of the Independent Television Service. For local information, check the website of your PBS station.

Before you leave this event, commit yourself to pursue one item from the brainstorm list.

## RESOURCES FOR FURTHER STUDY AND ACTION

<http://www.dystonia-foundation.org/> - The website of the Dystonia Medical Research Foundation provides a wide range of information about the disease, health care options, research, support groups, and an excellent collection of links to related organizations.

<http://www.dystonia-parkinsons.org/> - The Bachmann-Strauss Dystonia and Parkinson Foundation focuses on research. The website includes a downloadable brochure that answers frequently asked questions about dystonia.

<http://www.blinddogfilms.com/twisted/> - The website of the film profiles participants and provides downloadable publicity materials, and is the place to purchase copies of the film.

TWISTED WILL AIR NATIONALLY ON THE EMMY AWARD-WINNING PBS SERIES *INDEPENDENT LENS* ON TUESDAY, JANUARY 30, 2007 AT 10 PM. CHECK LOCAL LISTINGS.

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ITVS COMMUNITY is the national community engagement program of the Independent Television Service. ITVS Community works to leverage the unique and timely content of the Emmy Award-winning PBS series *Independent Lens* to build stronger connections among leading community organizations, local communities, and public television stations around key social issues and create more opportunities for civic engagement and positive social change. To find out more about ITVS COMMUNITY, visit [www.itvs.org/outreach](http://www.itvs.org/outreach).

