The film tells the great under-reported medical story of our times!

Ryan Prior
Coqui Pictures Presents
An Electric Puzzle and Blue Ribbon Foundation Production

FORGOTTEN PLAGUE

Directed and Produced By: Ryan Prior and Nicole Castillo
Executive Produced By: Mona Eliassen-Taliaferro
Cinematography By: Nicole Castillo
Edited By: Travis Preston
Original Score By: David Conley
Animations By: Sam Alkaitis

mecfsdocumentary.com
facebook.com/cfsdocumentary
LOGLINE:

A journalist afflicted with a mysterious disease embarks on a quest to find out why the CDC has neglected his disease and left millions sidelined from life.

SHORT SYNOPSIS:

Ryan Prior’s life imploded October 22, 2006 when he was struck down by a disease that dozens of doctors were powerless to diagnose, let alone treat. Against great odds, he becomes a reporter and ventures to tell the story of his suffering and improbable recovery. He is shocked that millions globally remain sidelined by the same disease, many bedridden for decades.

Forgotten Plague is a journey into the hidden world of myalgic encephalomyelitis (chronic fatigue syndrome). It is a chilling tale of our medical system’s failures in addressing many chronic, complex diseases. Yet it is also a riveting story of science’s remarkable ability to transform medicine and improve human life itself.

MEDIUM SYNOPSIS:

Ryan Prior’s life imploded October 22, 2006 when he was struck down by a disease that dozens of doctors were powerless to diagnose, let alone treat. The medical enigma, myalgic encephalomyelitis, denigrated as “chronic fatigue syndrome” by the CDC, becomes the greatest struggle of his life. Against great odds, he becomes a reporter for USA Today and ventures to tell the story of his suffering and improbable recovery. The piece strikes a galvanizing chord across the patient population and the outcry from readers is intense. They tell of lives lived for years bedridden in darkened rooms, tales of losing all support from family, colleagues, and friends. Some teeter on thoughts of suicide as the only outlet for a type of suffering the medical system doesn’t even recognize, let alone properly treat. As a journalist, Ryan feels he has a unique position, even a duty, to help bring this injustice to light. The response prompts him to enter into a much deeper investigation into the historic roots of the disease and into current and future research into finding its cause and ultimate cure.
Throughout the story, Ryan interviews doctors, scientists, journalists, and patients to get to the bottom of this perplexing medical mystery. Along the way he comes along breakthrough research that can finally objectively diagnosis this disease. However, at the same time, he sees more and more that the illness is far worse than he could have ever imagined. Although aware of the suffering from reading people’s stories, Ryan is continually shocked by the heartbreak and loss he sees firsthand. Each new story brings a profoundly new set of circumstances in which this forgotten plague has rocked a family and hollowed out a human life.

The journey is a perilous one. Ryan must deal with emergencies in which the encroaching disease nastily attacks back and nearly derails the production. And his co-director Nicole, ever stoic behind the camera, is affected in ways that catapult her from a neutral observer into a reluctant character in the unfolding drama.
Q&A WITH THE DIRECTORS

1- What was your motivation to leave your job as a journalist and make this documentary?

Ryan:
When working at Newsweek/Daily Beast, I was consciously aware of my desire to build an expertise in a certain subject and to do a long-form work as the best way to turbocharge my early career. I was primarily covering international affairs and the healthcare system, and imagined writing a book on some aspect of those topics. When my essays on ME/CFS for USA Today College started taking off, I knew I'd found the nationally significant story I was looking for. I think working on longer, deeper investigations is a lot more interesting than topically covering each new little breaking news items; as a daily newspaper reporter you are imprisoned by events. By working on a long form project, I could pour myself into something I cared deeply about, I could advance my career, and act in a far more creative, interdisciplinary way. I really value the daily grind of journalism, but I think longer, deeper projects are more agreeable to my constitution and allow me to spread my wings in a deeply satisfying way.

Nicole:
I was working in live news and the news that was covered on a day-to-day basis was about robberies, accidents, and domestic disputes; with 30 seconds allotted to each story. Stories would not get deeper than that. What I liked about making this documentary is that I could delve into an issue, and pay attention to all facets of the topic i.e. the personal stories about people that suffer from Chronic Fatigue Syndrome, to the lack of involvement by the medical community in Chronic Fatigue Syndrome, to the impact that CFS has on the U.S. economy. I liked that I could give the topic the attention it so desperately deserved rather than trying to cram it into a 30 second summary. Being in TV news was not something I was completely satisfied with because my ultimate goals were to do filmmaking for a living. When we started the documentary it was my opportunity to really jumpstart my career in a field I was very passionate about.
2- Who are your influences/mentors?

Ryan:
Within the medical documentary field, I'm a big fan of the Academy Award-nominated AIDS documentary How to Survive a Plague and of the Academy Award shortlisted film Under Our Skin, which is about Lyme disease. Many funders told us they wanted Forgotten Plague to be the “Under Our Skin” of our disease. I was also influenced by filmmaker Matthew Heineman's film Escape Fire on the American healthcare system and his work on HBO's Alzheimer's Project. With Forgotten Plague, I wanted to make a unique film unto itself, but one that built on some of the best techniques from these other acclaimed films. I wanted to use this film to put ME/CFS in the national dialogue the way these others films help put AIDS, Lyme, and Alzheimer's in the spotlight.

Nicole:
The filmmaker Werner Herzog is a big influence on me. His approach to documentary filmmaking encompasses many layers. He starts by introducing a topic, then, manages to show the universality of the human condition that his topic covers. One of my mentors is my cinematography professor. He taught me that telling a visual story is just as important as any dialogue you can have in a film. Conveying emotion is in the camera angles and the certain things you choose to shoot and include in the frame. I think knowing the fundamentals of visual storytelling helped me add my own style and layers that I aspire in emulating in my films. Telling the story of Chronic Fatigue Syndrome was crucial for the people who suffer from it and I wanted this film to give a genuine and true portrayal of the trials and tribulations of the illness.
3- If you had to do it over again, what would you do differently?

Ryan:
One recommendation we would have for those looking to direct their first feature-length documentaries is to spend a bit more time in pre-production. If we had spent 7-10 months preparing, introducing ourselves to bloggers/funders/key figures, and pre-planning some of the story, we likely could have reduced some of the headache later. For people looking to crowdfund feature films, it’s incredibly important to explain to them that crowdfunding isn’t magic. The longer you spend creating the architecture of your Kickstarter campaign, the more successful it will be. We crowdfunded $18,000 with only about a month of planning. Had we spent 6 months or more planning the campaign, we would certainly have surpassed that number by three or four times and then would have had less difficulty keeping the production going once the original funds had dried up (and before we got our 501c3 status).

Nicole:
We filmed a feature length documentary over the course of a year with a two-person crew. The rigor and tight schedule of the film shoot really called for a three or four person crew. With extra hands, I would have had a little more time to scout, locate and determine my lighting and camera scheme. Some of the spaces we were in were very tiny so it would have been nice to devote all my time to researching the area for interviewing. However, taking on many roles allowed me to experience and practice every aspect of production, which in some ways worked to my advantage in the long run.
4- What did you learn about directing this documentary?

Ryan:
I had finished my undergraduate degrees, in English and international affairs, only 5 months prior to starting the film. So this experience was akin to starting an intense interdisciplinary graduate school program in filmmaking, non-profit management, marketing, entrepreneurship, microbiology/public health, and journalism/PR.

The learning curve for each aspect of the film was intense. Setting out to make a movie seems like a really romantic idea, but the rubber hits the road when you're trying to keep all those balls in the air. On one day, I might be on the phone with the IRS about a tax-exempt status, and then fielding requests from donors/fans regarding my opinions on immune cells like interleukins and cytokines. All the while, I'm trying to speak to our animator regarding the latest storyboards he's created of the vagus nerve... and then sorting out personnel and payroll issues on our staff. To be honest, though, it's incredibly stimulating and incredibly fun. And that's actually because it's nearly impossibly difficult. When you succeed, it's even more glorious.

Nicole:
Directing a documentary has a very specific set of challenges. You have to wear many hats. I produced, shot the film, co-directed it, set up and recorded audio, organized interviews, set up housing arrangements, set up lighting, and so on. You can't cram too many interviews into one day. You have to spend a good amount of time with your subjects. Subjects are hesitant to open up at first, but the more time you spend with them, the more comfortable they feel to let you into their world. Building that trust is so important. Once you build that trust you will be surprised at some of the things you learn that goes beyond what you initially planned on asking about.
5- What challenges did you encounter while filming?

Ryan/Nicole:
Constantly running out of money and having to fundraise to pay our already meager salaries was the chief hurdle. We were very grateful when we ultimately found a strong, eager partner in our executive producer, Mona Eliassen-Taliaferro, which helped ease the financial pressure on us, the two co-directors, enabling us not only to pay our own paychecks, but to be able to bring on board a wide variety of about a dozen professionals to do specific jobs on post-production and distribution.

Besides that, perhaps the other great challenge was the mounting awareness that the global ME/CFS patient community was becoming increasingly reliant on Forgotten Plague to tell the story of the disease, and to magnify the efforts of advocates and researchers. As individuals, we were under significant personal and financial strain, but every day we received the most horrifying messages from sufferers. The stories were just unbelievable, and people usually ended their messages by saying “God bless you for what you are doing.” So many people told us they were praying for us. Waking up to those messages brings new meaning to each day. Knowing how vital and important this project was to sufferers across the world was both an immense blessing and a heavy burden. We had no choice but to succeed.

6- What is the audience take away from viewing this documentary?

Ryan/Nicole:
ME/CFS is a “forgotten plague,” an incredibly severe disease that the vast majority of doctors know little to nothing about. It affects three times the number of people that MS affects, and about as many as Parkinson's. The Annual economic burden, due to lost wages and inability to work, is $24 billion (about the same as Parkinson's). Yet the publicresearch budget for Parkinson's is about 24 times that of ME/CFS. The science on ME/CFS, as poorly funded as it is, is revealing physical, objective evidence for the disease that just leaps off the page. It demands greater funding and greater attention. It is, as our interviewee Ron Davis of Stanford has said, the last great disease for researchers to make their name in.

In terms of human impact, the disease devastates lives, rips families apart, and often leaves sufferers living bedridden in darkened rooms for decades.

Most importantly, the innovative immunological and genomic research that ME/CFS patients need is also the type of breathtaking science that will reorient the way biomedical science thinks about disease in general. The highest level researchers are fascinated by the disease and motivated by the human suffering. These include Columbia University’s Ian Lipkin, considered the world's foremost virologist. These include Nobel Laureate Jim Watson, who co-discovered the structure of DNA. Of course, there is Ron Davis, who won the highest prize in genetics, the Gruber Prize, for being an architect of the Human Genome Project. All of these scientists are hungry to see this forgotten plague solved. In short, ME/CFS is a disease whose time for radical solutions has come.
7- What change do you hope will come from making this documentary?

- About 94% of medical students will not receive proper education on ME/CFS during medical school, so we will work to have screenings of the film at medical schools and at medical conferences to help remedy the education gap.
- Many of the leading physicians in the ME/CFS field will retire in the next 5 years, so we will seek to help create a new generation of experts, particularly with our flagship summer Blue Ribbon Fellowship program for first-year medical students.
- The U.S. National Institutes of Health only allocates about $5 million annually for ME/CFS research; however based on societal burden of the disease, this number should be over $100 million annually. Funding for ME/CFS should be comparable to Multiple Sclerosis and Parkinson's. We aim to use the film to empower petitions and legislative advocacy in Congress for raising this disease on the list of funding priorities.
- Currently, most doctors believe that “chronic fatigue syndrome” doesn't have an objective diagnostic marker. However, that is false. The film, and the outreach around it, seeks to promote many of the emerging markers for quicker, more effective diagnosis for all sufferers. These include cardio-pulmonary exercise testing, high viral titers, low natural killer cells, and brain abnormalities.
- We seek to promote the adoption of the Canadian Consensus Criteria (CCC) and International Consensus Criteria (ICC) as the standard diagnostic criteria across government health agencies.

8- Do you plan on making more documentaries?

Ryan:
In college, I founded a magazine called the Georgia Political Review, which sought to ignite a independent non-partisan political discussion. I had felt sanity was being lost in our hyper-partisan media age. I recruited a team of about 30 students and led every aspect of creating, producing, and distributing the magazine. I see my work with Forgotten Plague and the Blue Ribbon Foundation as a continuation of that same social entrepreneurial spirit. I created a media corporation to help change the way people think about a highly pertinent issue. It's not just about creating a magazine, or a documentary, it's about creating a discourse. Going forward, I see my role in the world as to continue to look for pernicious problems which I feel I have a unique advantage in solving. I want to be engaged in creating stories and narratives that change the way people think about the problems. In the future, I might think of myself less as a writer or a filmmaker, but perhaps even most strategically as a digital media entrepreneur.

Nicole:
I absolutely plan on making more documentaries. The connections I made with the people I interviewed changed my life ... truly. If a film I make can help bring a truth or perspective out into the world of unheard voices or people in need, then I hope continuing in the process of moving a cause forward. Also, documentaries are a form of art and expression. I like how many facets must come together to make a film. You are creating a piece of art with many contributors, and I love that collaborative process.
9- Is filmmaking a more powerful medium to convey this story than print?

Ryan:
There are obviously myriad ways to tell the story of a disease: in newspapers, on broadcast news, in medical conferences, in medical journals, press releases, photographs, etc. But the medium of film, particularly a feature-length film of 80 minutes, helps encapsulate as much of the historical, political, medical, and personal aspects of the story in perhaps the most universal way. People watch the film, and more importantly, are moved by it, in ways they could never be motivated by a medical lecture. Most regular people would obviously never set foot in a medical school or medical conference. But nearly everyone watches movies. As a writer, I’m acutely aware that the novel was essentially the dominant mode of intelligent discourse in the 19th century. Today, it is film. In the early 1900s, muckraking journalists were exposing horrors of industrialization and corruption in long-form magazine pieces or novels like Sinclair’s ‘The Jungle’ which exposed the horrifying conditions of the workers in the Beef Packing Industry. Today, social justice documentaries are performing much of that same role and have a renewed potency because viewing film is a uniquely communal act, often done in large groups. And film can naturally bridge gaps as a multimedia and transmedia narrative: people see our film, can immediately tweet about it, sign online petitions, send letters to government officials, and spark change by engaging in the conversation. In the 21st century, digital media storytelling is the place to be.

Nicole:
Filmmaking can be a very powerful medium. When an audience can visually see the people a story is about, particularly in a documentary, it can make a story more personal to an audience because a person can see someone’s face, their reactions, their environment. What is powerful is that there is a vulnerability involved in letting a camera come into your home. When an audience can really see what a person experiences on a day to-day-basis they can feel more apart of a subject’s story.

10- Where do you go from here?

Ryan/Nicole:
We are so honored to have so much interest in our film from research, advocacy, and awareness groups all around the world. We have had hundreds of people sign up to stage screenings of our film. We are also honored and humbled to work with Patricia Finneran, one of the most skilled “Impact Producers” in the world. Working at the intersection of social entrepreneurship and digital media, she has created a set of structures and plans by which we can leverage the storytelling power of Forgotten Plague toward specific policy change goals.

Our non-profit, the Blue Ribbon Foundation, will continue working with key groups in our space toward goals for ME/CFS patients and researchers:

--Our Blue Ribbon Fellowship will empower medical students to spend their summers studying at top neuro-immune research institutes

--Our film will become a tool for medical education

--We will rally our audiences’ passions toward petitions for greater NIH funding for ME/CFS research, and for advocacy efforts toward adopting the CCC/ICC diagnostic criteria for ME/CFS as well as precise/accurate diagnostic tests
FACTS & FIGURES
FORGOTTEN PLAGUE

This isn’t just a movie.
Filming in 9 U.S. states
Nearly 100 interviews
80 hours of original footage recorded
$120,000 budget
2 trips to the emergency room during filming
Funding from 300+ donors across 8 nations
40+ choir members for the film's choral soundtrack recording

This is a movement.
Our goals:
1. Fundraising for Blue Ribbon Fellowship for medical students
2. Film to help educate doctors via Continuing Medical Education (CME)
3. A path toward a goal that every medical school includes ME/CFS in its curriculum
4. Petition for increased NIH funding for this disease (www.meaction.net)
Ryan Prior  (Co-Director, Producer, Writer)

Is a multimedia journalist and social entrepreneur. He was the founder and editor-in-chief of the Georgia Political Review and went on to jobs writing for The Daily Beast and USA Today. His reporting and commentary have also appeared in The American Conservative, Real Clear Politics, and several other publications. Currently working at CNN, he was selected as a 2014 Stanford Medicine X ePatient Scholar and was recognized as ProHealth’s 2014 ME/CFS Advocate of the Year. He is president of the Blue Ribbon Foundation and serves on the Board of Directors for #ME Action Network. He is a Phi Beta Kappa graduate of the University of Georgia.

Nicole Castillo  (Co-Director, Cinematographer, Producer)

Is a producer and filmmaker with a passion for social justice. She was the VP of Community Outreach for the University of Georgia chapter of Habitat for Humanity. A fluent Spanish speaker, she got her start working as a television journalist for Univision in Atlanta. From there she moved to Aero Film, a film production company just outside Hollywood, where she helped develop reality television programs with the creator of Survivor and helped film and produce the high-octane sci-fi thriller DRONE. She’s fresh off a stint as a 2nd AC for the feature film Treehouse. She holds bachelor’s degrees in Mass Media Arts and in Psychology from the University of Georgia.

Mona Eliassen-Taliaferro  (Executive Producer)

Since 1989, Mona steered Eliassen Group’s growth to include a resource pool of more than 130,000 contract professionals, becoming a valued partner to more than 1,200 companies, from Internet startups to Fortune 1000 companies. Considered a true pioneer as a woman entrepreneur, Mona has been chosen as a finalist for Ernst & Young’s “Entrepreneur of the Year” awards, been inducted into the Women’s Business “Hall of Fame” and selected as Incentive Magazine’s “Motivator of the Year.” She serves on the Women Business Enterprise National Council’s (WBENC) leadership forum and co-chaired the National Association of Computer Consultant Business’ (NACCB) 2005 Annual Conference. As an advocate for ME/CFS patients, she is Chair of the Board of the HHV-6 Foundation and serves on the Board of Directors for ProHealth. She earned a Bachelor of Science degree in Business Administration from Boston University.

Travis Preston  (Editor)

Travis is a Writer, Director, and Producer with 5 years of experience in the entertainment and media field. After attending the New York Conservatory for Dramatic Arts, School for Film and Television, he returned to his home state of Georgia hoping to build a network in the budding Atlanta film industry. In March of 2013, after interning on productions for ABC, Encyclomedia, and working with local independent filmmakers for several years, Travis formed, Electric Puzzle Productions in McDonough, GA. His clients have included Ford Motor Company and Wix. In September of 2013, Travis Directed Bad Indian, a web series that won critical acclaim and was accepted into the Toronto Web Series Festival and was featured in Buzzfeed and the Huffington Post.
**David Conley (Composer)**

Is an established composer, conductor and singer based in Princeton, NJ. David has sung in several world renowned choirs including The Hodgson Singers, winners of the Ave Verum International Choral Competition, The award-winning Westminster Choir, Westminster Symphonic Choir, and Westminster Kantorei, a 2014 finalist for The American Prize in Choral Music. He received his Bachelor’s Degree in Vocal Performance from The University of Georgia and is currently pursuing his master’s degree in Choral Conducting at Westminster Choir College.

**Sam Alkaitis (Animator)**

Is an animator based in Vancouver, British Columbia. He has worked as a Harmony Animator and Lead Build Artist for Bardel Entertainment. His credits include Cartoon Network’s Rick and Morty, which appears on Adult Swim. He holds a BS in Biology from the University of Virginia and a Diploma in Animation from the Vancouver Film School.

**Dan Schaefer (Sound Designer)**

Is CEO of the SoundNut, Inc. With over 18 years of experience in the Atlanta area, Dan is an award-winning audio engineer, sound designer and mixer. Past and present clients include Cartoon Network, CNN, Nickelodeon, Toon Disney/Disney XD, Boomerang, TNT, TBS, Turner South, Spike TV, The Weather Channel, Atlanta Motor Speedway, Gametap, Tribune Creative Services, WCW, Coca-Cola, Delta Airlines, BellSouth, Verizon Wireless, American Express, Hi-Fi Buys, Longhorn Steakhouse, WNNX and many others.
Lead animator, **Sam Alkaitis**, works with his assistant animator **Zakk Bottomley** adding their finishing touches for Forgotten Plague.

**Travis Preston** and **Nicole Castillo** post production. The working wall where a mere collection of scenes became a strong, cohesive story.

**Ryan Prior** in the studio with editor **Travis Preston** during production of Forgotten Plague.
Experts:

David Tuller  
New York Times, UC Berkeley

Ian Lipkin, MD  
Columbia University

Jose Montoya, MD  
Stanford University

Anthony Komaroff, MD  
Harvard University

Mike Van Elzakker (PhD Candidate)  
Tufts University

Leonard Jason, PhD  
DePaul University

Lori Chapo-Kroger, RN  
Pandora Org

Derek Enlander, MD  
Mt. Sinai Hospital

Hillary Johnson  
Former Correspondent for Vanity Fair, Life, Wall Street Journal, etc. and Author of Osler’s Web: Inside the Labyrinth of Chronic Fatigue Syndrome

Roger King  
Former Economist for U.N. Agencies and Author of Love and Fatigue in America

Linda Tannenbaum  
Open Medicine Foundation

Andreas Kogelnik, MD-PhD  
Open Medicine Institute

David Kaufman, MD  
Open Medicine Institute

Ron Davis, PhD  
Director, Stanford Genome Technology Research Center
Experts:

Ashley Davis—Director, Chronic Fatigue Syndrome Research Center
Stanford University

Staci Stevens, MD
Director, Workwell Foundation

Chris Snell, PhD
Professor of Exercise Science, University of the Pacific

Mark Van Ness, PhD
Associate Professor of Exercise Science, University of the Pacific

Dan Peterson, MD
Sierra Internal Medicine and Simmaron Research

Janet Smith, MD
Simmaron Research Board Member

Chitra Bhakta, MD
Orange County Integrative Medical Center

Jane Xenos, D.O.
Independent Physician

Judy Mikovits, PhD
Microbiologist

Charles Lapp, MD
Physician

Nancy Klimas, MD
Physician

Gordon Broderick, PhD
Computer scientist

William Pridgen, MD
Surgeon

Carol Duffy, PhD
Microbiologist
We expect big ideas to come from young people in computers, social networking and music. In medicine, less so.

So meet Ryan Prior, age 23, of Atlanta, Ga. He suffers from a little understood but ghastly disease of the immune system known in the United States as Chronic Fatigue Syndrome (CFS), and in the rest of the world as Myalgic Encephalomyelitis (ME).

The disease is mostly incurable; affects men and women, but more women than men are recorded; and the Centers for Disease Control (CDC) in Atlanta says there are 1 million victims in the United States and 17 million worldwide.

Its impact is horrific; confiscating lives, wrecking homes, sundering love affairs and grinding down caregivers and families. For the most part, the sick are sick until they die. Some are bedridden for years. Advocacy groups say suicide is high. I have received many letters from patients who say they can't take the pain, the helplessness and the stigma any longer, and beg for a quick release.

Despite all this, the disease gets short shrift from the National Institutes of Health and the CDC, although patients say they get a better hearing at the Food and Drug Administration.

“The message is simple: American history has progressed in a logical line from women's rights, through civil rights, then to gay rights. Medical history has a similar process of ridicule, repression and ultimate acceptance: MS, AIDS, and now we want CFS to be the next step.” Ryan Prior

Enter the over-achieving young patient, Ryan Prior. His story begins on Oct. 22, 2006. Like many victims he knows exactly when he was felled, when normal life had to be abandoned. He entered a dark world where good times are marked in hours; where bad times are days, weeks or months in darkened, silent rooms.

Prior was student president at Warner Robins High School in Warner Robins, Ga. (about 90 miles south of Atlanta), captain of the cross-country team and was taking three advanced placement courses. “My goal was to attend Duke University or West Point with the ultimate goal of becoming an Army Ranger,” he said. By Nov. 15, 2006, Prior had to quit school. Under a Georgia plan for educating sick students, “my physics teacher taught me heat transfer while I was lying on the couch,” he said. But he slept through calculus.
Ryan still hoped to make it as an athlete. During a brief respite, he was back on his soccer varsity squad. But it was a disaster. He had been put on a drug that provided a short energy boost. “I went to a practice and played for about five minutes. I did OK for the first minute. After five minutes, I realized I had to stagger off the field as soon as possible. If I didn’t get off voluntarily, I knew I would have to be carried off soon after.”

Prior was student president at Warner Robins High School in Warner Robins, Ga. (about 90 miles south of Atlanta), captain of the cross-country team and was taking three advanced placement courses. “My goal was to attend Duke University or West Point with the ultimate goal of becoming an Army Ranger,” he said.

By Nov. 15, 2006, Prior had to quit school. Under a Georgia plan for educating sick students, “my physics teacher taught me heat transfer while I was lying on the couch,” he said. But he slept through calculus.

Ryan still hoped to make it as an athlete. During a brief respite, he was back on his soccer varsity squad. But it was a disaster. He had been put on a drug that provided a short energy boost. “I went to a practice and played for about five minutes. I did OK for the first minute. After five minutes, I realized I had to stagger off the field as soon as possible. If I didn't get off voluntarily, I knew I would have to be carried off soon after.”

After seeing 15 doctors, who knew little or nothing about the disease, Prior found one who has helped him. Now, he says, he functions 90 percent of the time if he takes 15 to 20 pills a day and avoids overdoing it. Ultimately, he graduated Phi Beta Kappa from the University of Georgia.

But it's the almost complete ignorance of CFS by most doctors that has set Prior on his big idea project. He is making a documentary film about the disease with young filmmakers, and with a $12,000 budget. He hopes the film will lead to $50,000 in funding to create “an eight-week summer fellowship program” for medical students, between their first and second years, to study with recognized experts in CFS. They would, according to Prior, provide each student with a stipend of $5,000 for the eight weeks.

Prior has compiled a list of nine doctors or clinics preeminent in the field who he believes would accept the fellows. The end result: a flow of young doctors with a knowledge of CFS and new ideas.

I can attest that this is desperately needed. As far as I have been able to determine there are many states, including West Virginia and Rhode Island, where there are no doctors with specialized knowledge of the disease. One woman travels from Delaware to Manhattan for treatment with Dr. Derek Enlander, and many have moved Nevada to be near Dr. Dan Peterson in Incline Village and the Whittemore-Peterson Clinic in Reno.

If Prior’s plan works, it may lead to a much larger training effort in the United States and across the world.

“The message is simple: American history has progressed in a logical line from women's rights, through civil rights, then to gay rights,” Prior says, adding, “Medical history has a similar process of ridicule, repression and ultimate acceptance: MS, AIDS, and now we want CFS to be the next step.”

Llewellyn King
ProHealth's 2014 Advocate of the Year – Ryan Prior

ProHealth is proud to announce Ryan Prior as its 2014 Advocate of the Year. Each year ProHealth gives the award to an individual who has made outstanding contributions to the betterment of the ME/CFS community. Previous honorees were Jennifer Brea and Bob and Courtney Miller.

ProHealth founder, Rich Carson, says, “Ryan Prior is one of ME/CFS’s patient heroes who has gone to bat for every one of us by shining a bright light on the plight that sufferers experience every day. He’s a visionary who has made it his life’s goal to raise awareness, working tirelessly on behalf of patients to bring attention to this disease.”

Ryan was not your average high school student. By his junior year, he was captain of his high school cross-country team, president of the student council and a participant in NASA’s Student Launch Initiative – all while taking multiple advanced placement and honors-level courses. He had just returned from a summer in England where he studied writing and philosophy at Oxford University and had a poem selected for publication. An ambitious young man, he had his heart set on going to Princeton, Duke or West Point. He hoped to become an Army Ranger and ultimately pursue a career in writing.

Then on October 22, 2006, Ryan's life changed forever. “Something completely snapped,” he says, describing his abrupt introduction to ME/CFS. “By early November, I had withdrawn from high school completely. Teachers had to come to my house to teach me, sometimes by my bedside, provided I could hold my head up long enough for instruction, or stay awake long enough to finish a math test. I saw 16 doctors, none of whom had answers.

“That year remains the most pivotal of my life. I am 25 years old now, but those initial trials at age 17 will likely remain the most profound and difficult of my entire life. That was the year when the foundations of my character were forged in a crucible of intense suffering and uncertainty. I developed a new type of wisdom. My knowledge that I somehow found a way to navigate those dark days feeds me through every other hardship I've ever faced. Everything pales in comparison to the horror of having to fight this disease.”

Ryan was fortunate to find an excellent doctor in 2008, who had experience treating ME/CFS. Dr. Karen Bullington, of Atlanta, developed a treatment protocol to meet his unique needs. “I take about 20 pills a day (mostly supplements), give myself a shot once a week (methylcobalamin, glutathione, and other components), and get an IV treatment once a month,” explains Ryan. “If I neglect to take some of these things, I will fall back to being very disabled within a few weeks.” Dr. Bullington adjusts his protocol every few months based on his current needs.

The treatments were effective and Ryan’s health improved enough to allow him to continue his education at the University of Georgia. Despite two severe episodes where he almost had to drop out, Ryan managed to get through with the help of accommodations arranged by UGA’s Disability Resource Center.
By 2012, Ryan was a senior at the UGA. Following a six-month full-time internship at Newsweek, he began working as a Collegiate Correspondent for USA Today. Being both a patient and a writer, Ryan was acutely aware that his disease had, as he describes it, “a profound absence in the national conversation.” Therefore, he was constantly on the lookout for a news item about ME/CFS with enough national significance to justify him covering it for USA Today.

That fall, Ryan got the opening he was looking for – Dr. Ian Lipkin's study definitively disproving any link between the XMRV retrovirus and ME/CFS. Many news outlets reported the story, but Ryan's article had an important twist. Instead of writing a standard news story, he wrote an opinion piece, detailing his own personal trials battling the disease. The response was remarkable.

That initial article turned into a series of articles, which ultimately grew into the full-length documentary Forgotten Plague. “I had always planned on writing a book,” says Ryan, “but I felt that this was a story that might work better as a documentary. I partnered with my co-director Nicole Castillo, a very close friend at the University of Georgia, who was a cinematographer with a passion for social justice and health documentaries.” Forgotten Plague is described as the story of an afflicted journalist who “embarks on a journey to find out why the CDC and medical system have neglected his disease, leaving millions sidelined from life.

“The film tells the great under-reported medical story of our times, with threads detailing the politics, science, history, and deep human suffering associated with the disease, the film strives to give a panoramic picture of ME/CFS.” Ryan Prior

**The Making of Forgotten Plague**
Filming took Ryan, Nicole and their crew to eight states and the District of Columbia. They interviewed numerous experts, including most of the top ME/CFS researchers and clinicians. We asked Ryan some behind-the-scenes questions about the film.

**ProHealth:** How did you come up with the title Forgotten Plague?

**Ryan:**
At the end of shooting, we had a period of time to reflect on the totality of what we’d recorded. We wanted a pithy, impactful title that summed up the sheer magnitude of what we’d absorbed in our journeys across America. We heard the most devastating of stories each and every day.

The stress sent both my co-director, Nicole, and me to the emergency room. At times the content of the film was so emotionally fraught that Nicole fainted. Myself, I bottled up the trauma of the stories we heard, at times becoming emotionally numb. Some of the images now haunt me when I’m trying to sleep. I put my guard up, and tried to act like an objective journalist, not for professional reasons, but truly as a way to try and shield myself from
the force of pain and suffering that we were hearing from hundreds of people. Coping with this knowledge of suffering in the world is a trauma I will grapple with for the months and years to come. It's simply horrifying to me that there could be a disease this severe out there and that there could be such a profound lack of clarity and vision from the medical community on fighting it. That's why this film is called Forgotten Plague.

**ProHealth: What was the most moving part of the film for you?**

**Ryan:**
Working with the Davis/Dafoe family was the most moving experience. Many films or stories can boil down to a single moment or a single image or single anecdote. After interviewing hundreds of people, getting countless hours of footage, and surveying the global landscape, the entirety of the story can be reduced to a single family's story. The story combines our dual emphasis on innovative science and the human element.

Professor Ron Davis, of Stanford University, is one of the premiere geneticists in the world, a man who was present in most of the important moments in genetics in the past four decades, including each step in the Human Genome Project. Alongside Amazon founder Jeff Bezos and PayPal co-founder Elon Musk, Dr. Ron Davis is considered one of the people whom future historians will consider among today's greatest inventors. That was from an article published in no less a magazine than The Atlantic.

Now, also consider that Dr. Davis’ son, Whitney Dafoe, is in his 30s and has one of the worst cases of ME/CFS you can imagine. He's easily in the bottom 2% of patients. Top world experts say he's the most severe patient they've ever seen. Whitney has lost the ability to speak, lost the ability to eat, even lost the ability to perform the most basic communication, verbal or otherwise. Whitney is slowly, and devastatingly, wasting away. I cannot go a few hours without thinking of him. Whitney's suffering is forever weighing on my mind. I take many of the same pills that Whitney has been prescribed. What is the difference in our fates that I would somehow mount an improbable partial recovery while Whitney's destiny would decline so sharply in the other direction? We have the same diagnoses, almost all the same prescriptions, but remarkably different outcomes. The answer lies, of course, hidden deep inside the cellular and molecular signatures of this disease.

So you have a story of immense human suffering and immense human potential living under the same roof. One of the greatest of all living scientists, Ron Davis, is forced to contend with a reality that his magisterial intellect can do very little to save his son's life without a massive influx of funding. Millions and millions of dollars of funding is required for a man like Davis to lead the massive interdisciplinary science endeavor to save Whitney's life. Yet the federal government has not yet allocated that money. It's coming only in fits and starts from private donors.

Karen Lee Richards

“My hope is that by showing the Davis/Dafoe story on film, we can cut to the essential human heart of ME/CFS's devastation. My hope is that in telling that one, single story, we can build an unshakeable case for the change we need”. Ryan Prior
Availability of Forgotten Plague

Filming and post-production work has been completed and they are currently waiting on a release date. If you would be interested in showing Forgotten Plague at your home, school, community organization, or theater, you can sign up here. When the film is released, they will send you a Event Planning Guide and a Media Kit to show you how to plan your event. Eventually Ryan expects the film to be available via streaming services like Amazon, iTunes and others.