# UNDIAGNOSED THE FUTURE OF MEDICINE













# Most undiagnosed patients are likely to be suffering from a rare disease.

In the U.S. alone, rare disease patients are undiagnosed for an average of **7.6 years**.

There are an estimated

350 million people worldwide
living with a rare disease.



Lilly Grossman graduating high school, a day her family didn't know was possible. Lilly's story is a beacon of hope- the perfect example of how a diagnosis can change everything.

# Undiagnosed Film. Com

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# **ABOUT THE FILM**

#### **TRAILER**

Public Trailer (downloadable): https://vimeo.com/648777015

Private Trailer: www.undiagnosedfilm.com/trailer

\*This private trailer's music is more powerful, but it's not possible to license the music. Please use this version for any private sharing, but do not post publicly or on any socials.

#### **TECHNICAL INFO**

Title UNDIAGNOSED

**Tagline** The Future of Medicine

**Genre** Documentary

**Production Years** 2013-2021

Country of Origin USA

**Language** English

**Run Time** 90 minutes, 7 seconds

Screen Ratio 16:9

#### **LOGLINE**

<u>UNDIAGNOSED</u> combines science and compelling human drama to recognize a little-known issue devastating families worldwide: undiagnosed illnesses. Four families explore why the medical system is failing this population and how studying them will advance medicine for humanity. With the power of community, they push against rapid degeneration to find answers.

#### **SYNOPSIS**

<u>UNDIAGNOSED</u> is a 9-time award winning, feature-length documentary that brings forward remarkable cutting-edge science and compelling human drama to shine a light on a widespread but little-known issue devastating families across the world: undiagnosed illnesses.

Told through the stories of 4 different families, the film explores why the medical system is failing this population and how studying these patients will advance medicine for all of humanity. Combining genetic technology, the power of community, and unwavering parental love, these families push against the ticking clock of rapid degeneration to find answers.



Dr. Katia Moritz being interviewed by Nikki McIntosh for the Rare Mamas podcast

### **DIRECTOR'S STATEMENT - Dr. Katia Moritz**

Undiagnosed-I never thought about what it meant until I became sick and stuck in the worst moment of uncertainty, waiting for results but finding no answers. As a healthcare provider with decades of experience helping people, I thought I was well prepared to navigate the medical system. But the reality is that the medical system is not prepared for people like me. Looking to create a community, I stumbled upon a hidden epidemic of millions of people without an identity, whose stories needed to be told.

Recognizing the Undiagnosed allows us to validate their struggles and the very fact that they exist. Finding ways to help them and to save their critical health information became my life's mission. The discovery of new diseases and perhaps new treatments for known diseases hides in the mystery of their conditions, but their information is dying with them.

I embarked on a journey to document the stories of Undiagnosed families, and enlisted leading experts to create opportunities to collaborate and do things differently. We had the brightest minds in medicine helping us. The resulting 9-year project has yielded a powerful film containing intimate, compelling stories of hope and love, where families and doctors work together to impact the future of medicine.

#### THE FILMMAKERS

While searching for her own elusive diagnosis, Dr. Katia Moritz, a prominent psychologist, discovers a hidden epidemic of undiagnosed patients drowning in the healthcare system. She learns that the future of medicine is being robbed of their vital information-without a name for their illness, there is no database to store or cross-reference their medical cases, which could hold the key for finding treatments and cures to new and known diseases.

UNDIAGNOSED is the culmination of 9 years of work by Dr. Katia Moritz, the director and an undiagnosed patient herself — supported by an extraordinary team that includes Oscar and Emmy winning filmmakers, world-renowned scientists, and leading genetic technology companies.

#### TIMELINE

From 2013-2021, the documentary team captured over 800 hours of fascinating footage of undiagnosed stories across the USA. Showing innovative ideas about how diagnosis and data allocation can be successfully done, the film, in collaboration with Harvard Medical School and Boston Children's Hospital, created a worldwide "Diagnostic Challenge" for the undiagnosed patients whose plights the film has been following. The success of this initiative allowed for the creation of a collaborative consortium of biotechnology companies willing to take this proof of concept a step further.

UNDIAGNOSED is currently on a world wide educational tour, in conjunction with building an Impact Campaign containing initiatives aimed to improve the lives of patients, families, and the healthcare industries that serve them.



Caroline Yiu, concerned by the low oxygen beeping alerts coming from her son Alex's blood oximeter, nervously glances into the rearview mirror as father Bandy Yiu pats Alex's face and reminds him to take breaths.

"Intimate and powerful storytelling. The technical qualities are absolutely first-rate, the test being that we so quickly forget that these lives are being mediated by the narrative. We forget the cameras, forget the editing and just become absorbed in it all. Truly impressive work."



# "Best Documentary"

NYC Katra Film Series San Diego Film Awards Jacksonville Film Festival

#### "Best First Feature"

Toronto International Nollywood Film Festival **Denver Movie Awards** 

"Best Story in a Documentary" ""Best Hook - Documentary Feature" "Best Utah Filmmaker" Red Rock Film Festival

"Award of Excellence" Docs Without Borders Film Festival

#### **ACCOLADES**

9-time Award Winning

15 nominations for "Best Documentary" & "Best Film"

#### Selected at 25 film festival in 7 countires

I watched the film and was quite moved... The concept of the film- a medical documentary without a clear target- is like an action movie without a villain, and requires a different approach to talking about the circumstances and working our way through the drama. The film does so in a really impressive fashion."

- Brian Hu, Artistic Director, Pacific Arts Movement



**Geralyn Dreyfous Executive Producer** 

Geralyn Dreyfous is the co-founder of <a href="Impact Partners">Impact Partners</a> and has a wide background in the arts, long experience in consulting in the philanthropic sector, and is active on many boards and initiatives. She worked at the Philanthropic Initiative in Boston, which guides families of wealth in strategic giving opportunities and also taught Documentary and Narrative Writing with Dr. Robert Coles at Harvard University. Geralyn is also the Founder/ Board Chair of the Utah Film Center and a charter member of the Utah Coalition for Film and Media. Geralyn's executive producing and producing credits include the Academy Award winning Born Into Brothels; Emmy nominated The Day My God Died; and multiple film festival winners such as Kick Like a Girl, In A Dream, Dhamma Brothers, Project Kashmir, Miss Representation, Connected and The Invisible War.



Dr. Katia Moritz Creator, Co-Director

Katia Moritz, Ph.D., ABPP is a psychologist in Florida, New York, Utah, and Brazil, and is Board Certified in Cognitive and Behavioral Psychology. She is the co-founder and Clinical Director of the **Neurobehavioral Institute** and has dedicated her life to treating severe and debilitating anxiety disorders in children and adults.

In August of 2010, Dr. Moritz underwent a routine endoscopy and woke up with an unknown syndrome. After seeing doctors all over the country at various facilities, she is still undiagnosed. In her search for help she encountered a world of patients and families that were struggling with all of the same issues. The glaring need to foster awareness has inspired her to do something to initiate change. She created the feature length documentary *Undiagnosed* based on the stories of these patients, their doctors, and the medical system that is failing to service them.



Nicholas Miller Co-Director, Cinematographer

Crystal Shearman Producer

Nicholas and Crystal are a husband/wife team that own **Crowbait Pictures**, a boutique production company based in Park City, Utah and Vancouver, Canada. Since 2008, Crowbait Pictures has specialized in developing productions in formats ranging from short films, web series and music videos, to television pilots and feature films. Crowbait Pictures has rendered services for a tremendous number of Vancouver feature films and commercials, and has a particular passion for human interest documentaries. After learning about the undiagnosed population and the need for action, Nicholas and Crystal immediately got behind the idea of a documentary film. Together with Dr. Moritz and Dr. Hoffman, they have grown this project from a seed to the thriving movement that it is today.

# **KEYNOTE SPEAKER**

#### Katia Moritz, Ph.D., ABPP.

E. Katia Moritz, Ph.D., ABPP is the Chief Clinical Officer and the training director at the Neurobehavioral Institute. Dr. Moritz is Board Certified in Cognitive and Behavioral Psychology and a Fellow of the Association for Behavioral and Cognitive Therapies (ABCT). She is a licensed psychologist in Florida, New York, Utah and Rio de Janeiro, Brazil. Dr. Moritz is the creator and director of the feature length documentary UNDIAGNOSED. As a patient advocate and a mother of two children with a rare genetic disorder, Dr. Moritz has been a catalyst of multiple undiagnosed incentives. Her engaging and heartfelt presentations have moved and connected audiences to the important mission of the undiagnosed and rare disease community.



"As a healthcare provider with decades of experience helping people, I thought I was well prepared to navigate the medical system. But the reality is that the medical system is not prepared for people like me."

- Dr. Katia Moritz





# Companies that have donated applied technologies





















# **Grants & Donors**

# BLAVATNIK FAMILY **FOUNDATION**

TED LIONS C

Jerome A. Yavitz Charitable Foundation

NuView Life Sciences



Lineagen

# UNDIAGNOSED Impact Campaign Initiatives

The award-winning documentary that has captivated audiences around the globe is only the beginning! The UNDIAGNOSED team is mounting an Impact Campaign to raise \$200,000 towards improving the lives of patients, families, and the healthcare industry that serves them. Join us as we use the universal power of film to create positive healthcare changes and build a more knowledgeable global community.

www.UndiagnosedFilm.com/impact

# **Global Movie Screenings**

Worldwide UNDIAGNOSED educational movie screenings at schools, universities, libraries, medical teaching schools, medical institutions, community & patient advocacy groups, non-profits, government institutions & more!

# **Policy Influence & Genomic Reanalysis**

Support changes in regulation that allow patients who don't have a diagnosis to be covered for sequencing, but also periodic reanalysis of their genomic data until they are able to receive a diagnosis. Alex's story illustrates the power and importance of reanalysis.



Alex, previously undiagnosed for 10 years. His sister Elaine leads the nightly family prayer, which always consists of asking God for a diagnosis for Alex.

# The "Undiagnosed" Label

Much like how autism has become a commonly known and understood label for a broad range of behavioral conditions, "undiagnosed" needs to become a commonly understood, respected, short-hand label to describe medically complex cases that have not yet been able to find a diagnosis. This validation brings support to undiagnosed patients through the formation of a community, and the ability to move forward in their quest with medical professionals and insurance companies recognizing the patient's current state.

# **Specimen Repository**

Undiagnosed patient data & biological samples are essential to discovering new genetic illnesses, but there is no place to store this information. Tragically when an undiagnosed patient dies, their valuable information that could lead to diagnoses and therapies for others, dies with them. A Specimen Repository is needed to store these "cold case files" so they can be studied as new technologies are developed. ered for sequencing, but also periodic reanalysis of their genomic data until they are able to receive a diagnosis. Alex's story illustrates the power and importance of reanalysis.



Undiagnosed Camp held at the National Ability Center in Park City, UT.

For 1 joyful week, these kids were able to put aside the diagnostic odyssey and enjoy recreational activities with their entire families.

# **Undiagnosed Facts & F.A.Q.**

# How many people are "undiagnosed"?

The total number of undiagnosed patients is unknown but considered to be vast. To provide some perspective on this epidemic, consider that it takes an average of 7.6 years in the United States to uncover a rare disease diagnosis. Worldwide there are an estimated 350 million people living with a rare disease; add to those, patients still waiting for a diagnosis, patients who have been misdiagnosed, and adults and children who have diseases not yet named or recognized.

# What does "undiagnosed" mean?

Children and adults are considered to be undiagnosed if an explanation for their symptoms cannot be found over a reasonable period of time, despite repeated examinations. Why can't they be diagnosed? A few of the many, many possibilities include: The proper testing has not been conducted, or the tests that have been done were not performed or interpreted correctly; the right specialist has not been found; they have a known condition that is presenting in an unusual way; or, they have an illness that has not yet been understood or named.

# Why is the Undiagnosed population important?

Historically, investigating medical mysteries has led to some of the greatest break-throughs in treatment. Currently, when most undiagnosed children or adults die, there is no label, category, or database where doctors can file their medical information for future analysis. This results in losing a vast and untapped resource that could hold the key for discovering new diseases, furthering our understanding of current diseases, and finding new treatments and cures. The undiagnosed population has the potential to play a critical role in medical history.

# Do Undiagnosed people have any support?

Well-understood diseases, like cancer, often have charitable foundations raising money for research as well as patients, families and healthcare professionals that unite for mutual support. Being "undiagnosed" is not commonly considered to be an identity, but it should be. Simply creating a category called "undiagnosed" would give such individuals more of a sense of community and identity. Knowing you fit in fosters a sense of empowerment, purpose, and hope. Helping people who are ill feel that others are supporting and advocating for them, and know that they exist, can make all the difference in the world.

# What is it like to be Undiagnosed?

Without a diagnosis, patients often will not qualify for needed benefits or receive proper and compassionate healthcare. All they can do is to exist from day to day, feeling like they are drowning in confusion, desperation, and frustration. Living in a constant state of medical uncertainty is terrifying. Will I be able to continue working? Will my child live long enough to use their college fund? Many undiagnosed patients or parents of undiagnosed children are unable to plan for the next day, let alone any long-term future.

# "It's all in your head"

Without underestimating the complexities of differentiating medical and psychological conditions, a common thread that affects many undiagnosed patients is the tendency for doctors- sometimes out of frustration- to erroneously diagnose medically unexplained symptoms as psychiatric. Aside from the demoralizing effect this can have upon patients and their loved ones, the chances of a patient becoming accurately diagnosed in such instances are diminished. The words "it's all in your head" often imply that the patient is to blame, causing their symptoms on purpose, or "faking." Parents of children who have symptoms that cannot be explained can be at risk of being accused of causing the illness or of being neglectful or abusive. This is an important issue that needs more emphasis in medical schools and healthcare institutions.



Jeff Lowe, once a world famous mountaineer, has succumb to an undiagnosed illness that looks like ALS. He writes in his journal about how he will be donating his body to medical science in order to learn more about his disease, with the hopes of finding treatments and a cure for future patients.