

Present Moment Yogi Productions
In Association with Coalition Duchenne

Presents

DUSTY'S TRAIL

SUMMIT OF BORNEO



A Film By Catherine Jayasuriya, Allan R. Smith and Andrew Fink

Running Time: 64 minutes

Rating: Unrated

Language: English (some Bahasa Malaysia and Kadazan with English subtitles)

For More Information: dustystrail.com

Photos Available at: dustystrail.com

Publicity and Distribution Contact:

Catherine Jayasuriya
1300 Quail Suite 100
Newport Beach CA 92660
Phone: 1-714-801-4616
Fax: 1-949-721-9359
info@dustystrail.com

NOW IS THE TIME FOR HUMANITY TO COME TOGETHER

THE
INSPIRATIONAL JOURNEY OF A YOUNG MAN WITH
DUCHENNE MUSCULAR DYSTROPHY

PRESENT MOMENT YOGI PRODUCTIONS AND DREAMQUEST PRODUCTIONS IN ASSOCIATION WITH COALITION DUCHENNE
PRESENT

DUSTY'S TRAIL

SUMMIT OF BORNEO

PRESENT MOMENT YOGI PRODUCTIONS AND DREAMQUEST PRODUCTIONS IN ASSOCIATION WITH COALITION DUCHENNE PRESENT
DUSTY'S TRAIL - SUMMIT OF BORNEO A FILM BY CATHERINE JAYASURIYA, ALLAN R. SMITH AND ANDREW FINK FEATURING DUSTY BRANDOM DIRECTOR OF PHOTOGRAPHY AND EDITED BY ANDREW FINK
FEATURING MUSIC BY BOB MARLEY, PHILLIP PHILLIPS AND BRAX CUTCHIN DIRECTED BY CATHERINE JAYASURIYA PRODUCED BY CATHERINE JAYASURIYA AND ALLAN R. SMITH
FILMED ON LOCATION IN BORNEO AND CALIFORNIA FILMING BY ALLAN R. SMITH, ANDREW FINK AND CHUCK JONKEY SPECIAL THANKS TO THE PEOPLE OF SABAH, MALAYSIA, FRIENDS AND SUPPORTERS
AND THE DUCHENNE COMMUNITY WORLDWIDE

WWW.DUSTYSTRAIL.COM  WWW.COALITIONDUCHENNE.ORG

Winner of 6 Awards

9 Film Festival Selections

BEST DIRECTOR

St. Tropez International Film Festival

BEST DOCUMENTARY FEATURE

Los Angeles Movie Awards

BEST DIRECTOR

Los Angeles Movie Awards

BEST VISUAL EFFECTS

Los Angeles Movie Awards

AWARD OF EXCELLENCE

International Film Festival,
Indonesia

RIVER SPIRIT AWARD

Silent River Film Festival





KOTA KINABALU
INTERNATIONAL
FILM FESTIVAL **2013**



CREDITS

Directed by

Catherine Jayasuriya

Produced by

Catherine Jayasuriya

Co-producer

Allan R. Smith

Edited by

Andrew Fink

Director of Photography

Andrew Fink

Camera Operators

Allan R. Smith

Andrew Fink

Additional Camera

John Mokhtarei

Location Sound

Chuck Jonkey

Sound Mastered by

Juniper Post

Burbank, California

Sound Supervisor

David Kitchens

Supervising Sound Editor

& Re-Recording Mixer

Ben Zarai

Sound Effects Editor

Gonzalo "Bino" Espinoza

White House Photo Credit:

Chief Official White House Photographer

for President Barack Obama

Pete Souza

CAST

Dusty Brandom

Cath Jayasuriya

Neil Brandom

Lucas Brandom

Gabriella Brandom

Tan Sri Thomas Jayasuriya

Puan Sri Helen Jayasuriya

Jon Hastie

Pacien Cunningham

Azmi Calvin Bin George

Anthony Chang MD

Ron Victor MD

Stan Nelson MD

Rachelle Crosbie-Watson PhD

Thomas Collet PhD

Pat Furlong

Datuk Masidi Manjun

Richard Hoare

Amir Yusoff

Richard Sokial Nelson

Bastien Ciocca

Cynthia Ong

Cris Dedigama

Ian Henderson

Sapinggi Bin Ladsou

Robbi Bin Sapinggi

Mindy Cameron

Polly Sundeen

Linda Rang

Beth Kilgore

Kim Innabi

Tham Chew Yen

Junaira Bin George

Evan Romano

Madison Blaylock

Cameron Kelley

MUSIC

“One Love/People Get Ready”
Written by Bob Marley and Curtis Mayfield
Performed by Bob Marley & The Wailers
From the album “Exodus”
Tuff Gong
Under license from Universal Music Enterprises

“Home”
Written by Drew Pearson and Greg Holden
Performed by Phillip Phillips
From the album “The World From the Side of
the Moon”
Interscope
Under license from Universal Music Enterprises

“Everybody’s Here”
Written and performed by Brax Cutchin
From the album “Meet You in the Fall”

“Goodbye Versailles”
Written and performed by Hey, Marseilles
From the album “To Travels & Trunks”
Onto Entertainment

“Wet the Day”
Written by Jimmy LaValle
Performed by The Album Leaf
From the album “One Day I’ll Be On Time”
Tiger Style Records

“When You’re Somewhere”
Written and performed by Mark McGuire
From the album “Get Lost”
Editions Mego

“Blood”
Written and performed by The Middle East
From the EP “Recordings of The Middle East”

“In the Dirt”
Written and performed by S. Carey
From the Album “All We Grow”
Jagjaguwar

“Coahuila”
“March 4, 1831”
Written and performed by Balmorhea
From the Album “All is Wild, All is Silent”

“Tinggi Tinggi Gunung Kinabalu”
Performed by Sapinggi and Robbi
Traditional

SYNOPSIS

DUSTY'S TRAIL: SUMMIT OF BORNEO is an inspirational documentary about a young man's journey with Duchenne muscular dystrophy (Duchenne), a fatal and debilitating muscle wasting condition that affects one in 3,500 boys worldwide. The story tells about people coming together from around the world to climb a mountain in Borneo for charity to raise awareness for Duchenne. DUSTY'S TRAIL: SUMMIT OF BORNEO celebrates life through the ties that bind all humanity. It's about the power of creating a positive, happy, fulfilling and inspiring life when the odds seem against it. Filmed in Borneo and California, the documentary is based on interviews with doctors, researchers, parents, friends and people who have been inspired by Dusty's life, some with whom he has never met, and others who share the same path.

LONG SYNOPSIS

DUSTY'S TRAIL: SUMMIT OF BORNEO, is an inspirational story about Dusty, a 20-year-old young man with Duchenne muscular dystrophy (Duchenne).

When Dusty was young, he seemed like any other normal child – happy, playful and smart. However, Dusty could never run, hop, or jump. What his parents and doctors thought were just delays in physical development, actually revealed a more devastating reality. Dusty was diagnosed with Duchenne at age six.

Duchenne is a genetic, fatal, progressive muscle wasting condition that affects one in 3,500 boys worldwide. It cuts across countries, cultures and races. Duchenne does not affect the mind. Dusty went from walking at age six, to a wheelchair by age nine.

The diagnosis of Duchenne meant that every muscle in Dusty's body was going to steadily weaken for the rest of his life until the heart and breathing muscles stop functioning. Tragically, many young men with Duchenne die in their early to mid 20's.

DUSTY'S TRAIL: SUMMIT OF BORNEO tells about people coming together from all around the world to climb a mountain in Borneo for charity to raise awareness for Duchenne.

Filmed in Borneo and California, the documentary is based on interviews with doctors, researchers, parents, friends and people who have been inspired by Dusty's life, some with whom he has never met, and others who share the same path.

Throughout Dusty's life, Duchenne continues to steal many things: his ability to walk, to lift his arms, to comb his hair, to hug, to cough, to breathe independently. Confined to a wheelchair, he sits in a tightly fitted orthotic seat that accommodates a spine twisted by scoliosis. Dusty has endured a gradual loss of all physical ability, whilst at the same time having a mind like any other young man's. In the last few years, Dusty has experienced weakness in the muscles of his heart and diaphragm.

Whilst his journey has been filled with the ups and downs of living with Duchenne, his spirit thrives. His strength and resilience have stood up to the challenges thrown at him. Dusty transcends the harsh reality of Duchenne to a higher reality of a life filled with love, happiness, laughter and peace.

DUSTY'S TRAIL: SUMMIT OF BORNEO celebrates life through ties that bind all of humanity. It is about the power of creating a positive, happy, fulfilling and inspiring life when the odds seem against it.

THE EVOLUTION OF DUSTY'S TRAIL: SUMMIT OF BORNEO

Catherine Jayasuriya has worked relentlessly to make a difference for boys and young men with Duchenne since her son Dusty was diagnosed at age seven. She founded the non-profit charity, Coalition Duchenne in 2011, and created a global event in Borneo, her childhood home, to climb its highest peak Mt Kinabalu to raise awareness for Duchenne. Expedition Mt Kinabalu was born.

"I wanted to make a film to tell the world about what my son Dusty and other young men with Duchenne go through. Earlier this year (2012) I was fortunate to meet filmmaker Allan Smith and editor Andrew Fink. I shared my ideas and asked them to come with me to Borneo, not only to film this documentary to raise awareness for Duchenne, but to climb a 13,455 ft mountain. We had a great team!"

"Present Moment Yogi Productions" was created with the express intention of making inspirational documentaries. DUSTY'S TRAIL: SUMMIT OF BORNEO is our first project. We are excited by the response to the film."

DUSTY'S TRAIL: SUMMIT OF BORNEO is a product of friendships encountered on Catherine's journey through the ups and downs of having a son with a fatal, incurable condition.

DIRECTOR/PRODUCER CATHERINE JAYASURIYA PROVIDES SOME BACKGROUND

"I was born to a Malaysian father and an English mother. More specifically, my father is part Sri Lankan and part Kadazan. The Kadazans, also known as the Kadazandusuns, are the largest group of indigenous people of Sabah, in Malaysian North Borneo. My parents met when my father won a scholarship to study law in England in the 1950's.

I am fortunate to have lived my childhood in Sabah. I was raised in the then small town of Kota Kinabalu. In the 1960's, KK and its surrounding area were largely undeveloped and I spent my childhood running around on the beaches, the islands and hills, and exploring the rivers and untouched rainforests. It was an idyllic setting. I was growing up and living in an adventurous and exotic place. To me it was paradise.

As a child, what fascinated me the most was Mount Kinabalu, a tower of granite that rises majestically 13,455 ft above the surrounding countryside. Mount Kinabalu has been a silent reminder of time passing. The mountain was like a loyal friend in my life, constant and unchanging. It was witness to all that was happening.

Mount Kinabalu is an isolated batholith, created 15 million years ago. It boasts being the highest mountain between the Himalayas and Irian Jaya, Indonesia. Mount. Kinabalu has attracted the attention of botanists since 1894 because of its diverse flora.

The word Kinabalu comes from the Kadazan word Aki Nabal, "revered place of the dead". The mountain is sacred to the Kadazans. They believe that spirits of their ancestors inhabit the top of the mountain. Many Kadazans still live in small villages or kampongs on the flanks of Mount Kinabalu.

In my childhood days, it was a slow nine-hour drive to the mountain and the park headquarters, along a winding, treacherous dirt road that created havoc for vehicles during the rainy season. I remember one time that our four-wheel drive had to be towed up a slippery, muddy hill by a steamroller. Today it is a fast hour and a half drive.

At age 11, I was sent to boarding school in the West. Over the years I would return for holidays, and KK changed dramatically. The rainforests began to vanish, the dirt roads were replaced by modern roads, the clear flowing rivers silted up as development made way for modern buildings, more roads and the arrival of tourism.

Not only did I stand in the worlds of East and West but also those of old and new. Mount Kinabalu was a witness to all these changes. On each return I contemplated the magnificence of the mountain, strong and undefeated. And I decided that I too would stand strong and undefeated.

No matter where I was, whether I was out on my favorite island Mamutik, lying on my thinking rock, surrounded by tranquil waters, or watching from my home, seeing the dark rain clouds clear and unveil the mountain after a raucous tropical storm, it was impossible to escape Mount Kinabalu's magnificent presence.

Mount Kinabalu became a symbol for my life. The mountain watched over as the years passed. Like an anchor, the mountain reminded me where I was from and kept on drawing me back, guiding me through some difficult years while I was away from home. Every time I left to go back to boarding school, I would look at the mountain one last time and blink it into my memory. Mount Kinabalu stood for wisdom. It spoke to me of strength and endurance. Throughout life's ups and downs the mountain remained the same, and so did a certain part of me. It reminded me that despite the changes that life brings, there are fundamental things that always stay the same.

Although I have lived in many countries, I still call Sabah home. Despite the changes, when I visit I can still feel the old KK that I knew as a child. It is the remnants of old buildings and roads that conjure up memories of a much simpler life.

For the past two years I have returned home to Sabah to lead an international expedition to climb Mount Kinabalu. It is a personal quest.

I climb to raise global awareness for a little known condition called Duchenne - the most common devastating genetic childhood condition and affects one in 3,500 boys worldwide. Boys and young men with Duchenne face progressive muscle wasting that robs them of their ability to walk, breathe, eat and speak and eventually takes their lives often before they reach the age of 20. It leaves their minds unaffected and full of dreams. Duchenne occurs across all races, cultures and countries.

My son can never join me on this climb. Just after dawn before the morning clouds hide Mount Kinabalu behind a heavy cloak of mist, he watches from his wheelchair, as climbers from around the world take on the slopes of Mount Kinabalu, to climb in honor of him and all boys and young men who suffer from Duchenne."

DIRECTOR/PRODUCER CATHERINE JAYASURIYA DISCUSSES THE PROJECT

Why did you make a movie?

It is my son Dusty who inspires me. The idea was to make a movie about Duchenne around our annual charity Mountain climb. I wanted it to be something positive that would involve a lot of people coming together. I thought that would be a really fun thing to do.

How did you think of the title DUSTY'S TRAIL?

When I was a child growing up in Sabah in the 1970's, there were one or two shows I used to watch on TV. There was an American western/comedy show called Dusty's Trail, set in California. The show epitomized everything Californian for me. When my son was born in California, all these years later,

the name Dusty just came to me. Dusty's journey with Duchenne has created a trail of love and gratitude.

What are your hopes for this production?

Predominantly, my hope is to raise global awareness for Duchenne. I want the world to know what my son goes through and what all the boys in the world with Duchenne go through. All over the world there are young men with Duchenne and families going through the same thing. It's the same shared journey and it's a story that needs to be told. I wanted to do something that will make a difference.



You feature several boys and young man with Duchenne, what is the outlook for them?

I don't really look at it that way. I don't think it's about a diagnosis or prognosis. I think it's really about enjoying the present, realizing to be grateful every day. In a way we all have a terminal illness, we're not going to be here forever. These boys inspire me because they deal with their challenges so well, they're so happy and positive, and I just want to do something for them.

You've documented Duchenne in a third world setting. That would be at first, correct?

Yes, it probably is. That was something that was not planned, it just happened. Someone got in touch with me and told me of a family who had a 14-year-old with Duchenne, and it just so happened the film crew was there and I took them with me to visit the family. The family were poor, and the young boy sat on the floor.

How did the people of Sabah respond to you and your crew?

Sabah is my home. The people are very warm and welcoming. They are very friendly people, they don't take life so seriously and I think they found it quite fun. They saw the film crew get sick and also tired from climbing the mountain. We all laughed about it together!

What was the greatest challenge for you in making the film?

I think the challenge was that I was not only making the documentary but I was organizing the expedition climb. We had 62 climbers. It was quite overwhelming; I just had to take each day at a time. There was so much to do and also I had to think about documenting shots at the mountain, shots at the islands and all these very symbolic places. I had to juggle these things but also take the time to be present and being aware of the people I was with and the whole process of the documentary we were creating.

What was the highlight of the filmmaking process?

I think the highlight was that it was brand-new to me and I learned so much and I met great people. I think we have a great team. The way the footage came back and the way the film was edited and evolved was just fascinating. It was so exciting, the fact that we had this great footage and we were going to create something incredible, and I think we did that. So much love and care went into the editing of the film and that shines through.

CO PRODUCER ALLAN R. SMITH DISCUSSES THE PROJECT

How did you meet Catherine Jayasuriya?

I first met Cath when she called about filming the climb for Coalition Duchenne. We later met at a coffee house and I must say that I was most impressed with this mother and her determination to bring awareness to Duchenne.

Had you ever heard of Duchenne?

No! Surprising I have been involved with the fire service and I was familiar with muscular dystrophy in general and the fill the boot drive (a fundraising effort done in conjunction with the Muscular Dystrophy Association (MDA)). However, Duchenne was something I had never heard of and was totally taken by surprise.

What were your thoughts when you met Dusty?

When I first met Dusty, I thought here is a blond haired kid with a smile that could be seen forever. What a personality and positive attitude! At first you have to wonder with the diagnosis of Duchenne, how can you be so positive? Then you realize that this is how these kids are and Dusty, well he is an inspiration to everyone!

Was this your first trip to SE Asia?

I have filmed around the World and recently in Indonesia. But Borneo was a first for my crew and me.

What were your first impressions of Kota Kinabalu?

At first when you see Kota Kinabalu, I had to make sure I was in Borneo. I have heard about the history of Borneo, but certainly did not expect a city the size of Kota Kinabalu. The city has everything and the people were some of the most friendly and outgoing I had ever met. I would love to go back!

What is your basic philosophy in capturing people for documentaries?

Bring out the truth! Get to the core of the story and capture every moment.

Who has inspired your documentary style? Can you describe your style?

I think, I like to think, I am my own person and kind of created my own style. Of course for years I have seen Ken Burns and Warner Herzog films that I admire. But in saying that, my style is to find stories that have not been previously told on film. To really find that "one" story that will make the difference in people's lives after they leave the theatre. We did that with *Rescue Men – The Story of the Pea Island Lifesavers* and I feel we are doing it again with DUSTY'S TRAIL: SUMMIT OF BORNEO.

What was the most difficult aspect of filming DUSTY'S TRAIL: SUMMIT OF BORNEO?

For my crew and me, it was the environment. You also deal with humidity, rain and constant changing weather. Then when we arrived on the mountain, it changed from tropical heat and humidity to cold, difficult climbing. Keeping the equipment dry, batteries charged and the gear in working condition was a priority. Additionally, we needed to capture the climbers as they were struggling up the mountain. Thankfully Andy (Fink) kept in the lead with Catherine (Jayasuriya), and Chuck (Jonkey) and I followed the pack.

Can you recall an amusing anecdote or event during filming?

Oh, wow there's a great question. Well unfortunately you hear the story of eating street food in a third world country and getting sick? In a five-star hotel at the celebration dinner after the climb, surprisingly I ate something bad and it put me down for the count. I think I was down for two days and as I'm someone that says, "Oh I eat everything and never get sick", it must have been pretty comical to be on the outside looking in at my moment of difficulty.

EDITOR ANDREW FINK DISCUSSES THE PROJECT

Had you ever heard of Duchenne?

Before embarking on this project, I had never head of Duchenne. I've been exposed to Muscular Dystrophy, but never had I seen nor experienced Duchenne.

What were your thoughts when you met Dusty for the first time?

Being around those who are disabled or wheelchair bound isn't exactly a new experience to me. But, when I first met Dusty the first thing I recall was his smile. Aside from that, it was just like any other interaction with someone I first meet.

What were the biggest challenges in working on Dusty's Trail?

The hard thing was finding and creating a story with several different elements. Even in Borneo we were all unaware of how exactly all of these things would fit together. It wasn't until after we got back from Malaysia did we sit down and realize what else we needed to capture, who else we needed to interview, and how will all these pieces come together into an hour long movie that flows effortlessly. We chose not to have a voiceover narrative and instead have the cast tell the story in their own words, which was a challenge in itself.

Has the editing retreat in Oceanside been helpful?

In order to immerse yourself into a story and look at everything from all sides, it takes a bit of reclusiveness. I've found that is what helps me work best. Shutting myself off and editing without distractions. Having a retreat down to Oceanside for about seven days provided that space for immersion and creativity and story building. It was extremely helpful for us all to sit and watch and discuss.

How has the film changed you?

Being involved with this film, this life and this world of Duchenne, has been a humbling experience. Before this project, like the majority of the world, I was unaware of Duchenne and how it affects thousands and thousands worldwide. Witnessing different aspects of this world and being saturated within the community has made me realize how powerful and beautiful the human spirit can be. Seeing Dusty smile, feeling the love that surrounds him everyday and having the opportunity to tell this global story, is an inspiration.

Any challenges in post production?

The real challenge in Post Production for me was finding that time and mind set to fully immerse myself in this story. It was difficult with such a small crew and few key players on the project. For myself, finding the balance and time managing multiple projects at once, while developing this story as we shot it, was the main obstacle I had to overcome. Patience and understanding was essential for us all.

DUSTY BRANDOM DISCUSSES THE PROJECT

What was it like to see yourself on the big screen?

When I saw my face up on the big screen, it was strange but I ended up getting used to it. I've been part of the editing process so I have seen the film so many times! But what's important is that others see what it's like to have Duchenne, and hopefully the film will help other families and boys and young men with Duchenne like me, going through the same thing. Awareness is very important.

What is the message you most want to convey to people about Duchenne?

The message is to be kind and understanding of those with Duchenne and people with all kinds of disabilities. I think people with Duchenne are just like regular people. Our bodies may be weaker but our minds are okay. It's important to accept each other and to find what not separates us but what brings us together. President Obama has inspired me in this sense. When I met President Obama in 2011, he was very cool. He knew that I didn't have the strength to shake hands so he held my hand and my shoulder. The President made me feel very comfortable. He was very understanding.

How do you manage to stay so happy?

I do what I like doing. I don't really think about Duchenne and I just don't focus on it. I really enjoy my day and everything in it. People sometimes ask me whether I miss being able to play sports or run. Not at all. I have so many things I can do and it is easy to have fun. I have many interests. I'm busy most of the day. At the moment I'm really into astronomy and I enjoy looking at the stars and planets through my telescope.

SOUND AND MUSIC

DUSTY'S TRAIL: SUMMIT OF BORNEO integrates the timeless classic "One Love" by Bob Marley with new mainstream artist Phillip Phillip's "Home" and lesser known but compelling tracks by Brax Cutchin, Mark McGuire, S. Carey, Balmorhea and others.

Catherine grew up to the sounds of Bob Marley. His music formed the backdrop for much of her teenage and family life. She fondly recalls travelling in Jamaica after Dusty was diagnosed with Duchenne and her sons Dusty and Lucas singing *Three Little Birds* whilst driving along back island country roads. Marley's seminal One Love provided the catch cry for Coalition Duchenne's annual Music Power fundraiser: "One love, one heart, let's get together and feel alright".

The team captured Kadazandusun guides in Borneo singing the traditional "Tinggi Tinggi Gunung Kinabalu" and that is used as a backdrop to the initial climbing sequences.

Audio post mixing was done by Juniper Post, an Emmy Award winning facility in Burbank, California. With over 300 films & TV shows completed since 1983, Juniper Post has greatly enhanced the film's audio which was often captured in difficult conditions.

CAST AND CREW

The true "stars" of DUSTY'S TRAIL: SUMMIT OF BORNEO are the boys and young men with Duchenne. Director Catherine Jayasuriya said they inspired her to make the film. Catherine wanted the world to see what they go through and the importance of humanity coming together, to care and to make a difference in the lives of boys and young men with Duchenne.

BIOGRAPHIES



Dusty Brandom, California, USA

Dusty is 20-years-old and has Duchenne. Dusty lives with his family in Newport Beach, California. He graduated from Corona del Mar High School and is starting undergraduate classes at the University of California, Irvine. Dusty serves on the board of Coalition Duchenne and has worked to raise awareness for Duchenne and funding for research. He is participating in the ground breaking FDA trial of Ataluren at University of California, Davis. Earlier, the Dusty Brandom Fellowship funded doctoral students investigating oligonucleotides at the University of Western Australia – research that is being developed by different companies and is now proceeding into trials.

In 2011 Dusty met with President Barack Obama in the White House and spoke to him about Duchenne and his family's cause to raise awareness and funding. The President said that he carries Dusty's story in his heart. Dusty is known for his positive outlook on life, and his great smile.



Azmi Calvin Bin George, Sabah, Malaysia

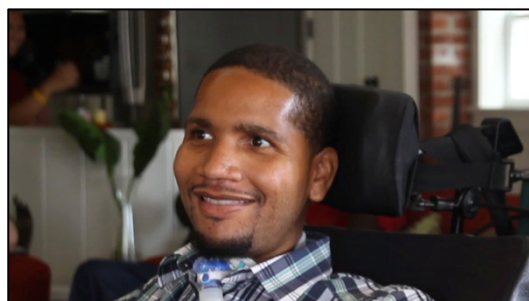
Azmi is a 14-year-old who has Duchenne. He lives with his family in Menggatal near Kota Kinabalu in Malaysian Borneo. Azmi is one of six siblings, and his family welcomed the Dusty's Trail film crew to their home. Azmi played an important role in flagging off the 2012 Expedition Mt Kinabalu with other dignitaries.



Jon Hastie, West Sussex, England

Jon is 31-years-old and has Duchenne. Jon lives independently in Worthing, West Sussex, UK, supported by caregivers. Jon has very little mobility throughout his body, eats only pureed food and needs to use a ventilator to help his breathing for about 16 hours a day. Jon works part-time at a local disability organization and is an active campaigner for the rights of the disabled. He has a Bachelor's Degree in Politics and International Relations, a Master's degree in Environmental Studies and a Ph.D. in Government.

In 2011, Jon made an inspirational film, *A Life Worth Living – Pushing the Limits of Duchenne*. Jon enjoys a good glass of wine or two with friends down the pub, and enjoys cinema, theatre and comedy shows.



Pacien Cunningham, California, USA

Pace is a 32-year-old with Duchenne living in Los Angeles, California. He is of Native American, German, Danish, and West Indian (Virgin Islands) heritage. Pace is a mentor, advisor, and a specialist in teaching disabled individuals to become independent, like him. He travelled to Oceanside, California to participate in filming for Dusty's Trail and kept the crew amused with his humorous comments.



Datuk Masidi Manjun, Sabah, Malaysia

Datuk Masidi is Minister of Tourism, Culture and Environment in the Malaysian state of Sabah, Borneo. Known as 'Minister on the Move', he has established himself as a dynamic advocate for the people of Sabah. Datuk Masidi has been supportive of Coalition Duchenne and Expedition Mt Kinabalu since its inception. He immediately saw the value to Sabah of having one of its own, Catherine Jayasuriya, promote the state as part of her efforts to raise awareness for Duchenne



Neil Brandom, California, USA

Neil lives in Newport Beach, California with his family. His oldest of three children, Dusty, has Duchenne. Neil is a civil engineer and principal of a California-based real estate developer. Neil was born in Sierra Leone, and lived in England and Australia prior to making his home in the United States. He joined the board of Parent Project Muscular Dystrophy in 2003, and served as the Chairman from 2005 through the end of 2007.



Patricia Furlong, Ohio, USA

Pat is the founding president and CEO of Parent Project Muscular Dystrophy, the largest non-profit organization in the United States solely focused on Duchenne. Its mission is to improve the treatment, quality of life, and long-term outlook for all individuals affected by Duchenne, through research, advocacy, education, and compassion.



Lucas Brandom, California, USA

Lucas is an 18-year-old from Newport Beach, California. His older brother Dusty has Duchenne. Lucas is an accomplished musician and enjoys playing bass and guitar.

Lucas feels a connection to Sabah as his great grandmother was Kadazandusun. He climbed Mt. Kinabalu in 2011, as part of the inaugural Expedition Mt. Kinabalu. In 2012 Lucas returned to Borneo with two of his high school friends to be part of the second climb. "I climbed for my brother

Dusty. We raised a tremendous amount of awareness for Duchenne in Malaysia and the film will raise even more worldwide," said Lucas.



Catherine Jayasuriya, Director, Producer

When Catherine's son, Dusty, was diagnosed with Duchenne 14 years ago, it was a catalyst for her to live in the present moment and to live with gratitude. Catherine is Malaysian/English. Her father is part Sri Lankan and part Kadazan, and her mother is English. Catherine was raised in Kota Kinabalu, in the Malaysian state of Sabah, on the island of Borneo. She is proud to say she is Sabahan, and although she has lived in Australia, England, Canada, and currently the USA, she still calls Sabah home.

Catherine has undergraduate degrees in Asian History and Photojournalism, and a Masters in Counselling.

Catherine is founder of Present Moment Yogi Productions, which is committed to making a difference in the world with inspirational messaging through the medium of film and documentary. She also founded a non-profit organization called Coalition Duchenne that raises awareness and funding to find treatments and one day a cure for Duchenne.

Catherine enjoys hiking, writing, travel, teaching yoga and spending time with her family.



Allan R. Smith, co-producer, Camera

A leading adventure filmmaker and president of DreamQuest Productions, Allan has filmed around the world, from the jungles of South America, to the Mojave Desert, to Everest Base Camp, to the cold of the Alaskan tundra. Allan was most recently recognized with industry awards for his documentary “Rescue Men – the Story of the Pea Island Lifesavers”.

Before meeting Cath Jayasuriya, Allan had never heard of Duchenne. “Having filmed around the world for 30 years, I was shocked to learn about this debilitating form of muscular dystrophy. Knowing about Duchenne and Coalition Duchenne, first you realize how fortunate you are, then you realize that this is something that must be addressed and a cure found”.



Andrew Fink, Editor, Camera

Andrew’s passion of editing and camera work sprouted from a life of skateboarding, water sports and constantly being outside. Andrew graduated from Tribeca Flashpoint Academy and has worked on numerous documentaries, short films, music videos, promotional and corporate videos as well as editing a feature documentary that debuted at the Chicago International Film Festival.

“Allan Smith nonchalantly asked if I wanted to travel to Borneo and climb the highest peak in Malaysia. Little did I know what a life changing experience it would all be,” said Andy.

“Being involved with this film, this life and this world of Duchenne, has been a humbling experience. Before this project, like the majority of the world, I was unaware of Duchenne and how it affects thousands and thousands worldwide. Witnessing different aspects of this world and being saturated within the community has made me realize how powerful and beautiful the human spirit can be. Seeing Dusty smile, feeling the love that surrounds him everyday and having the opportunity to tell this global story, is an inspiration”.



Chuck Jonkey, Sound

Chuck Jonkey is a traveller who transforms his wild experiences into sound, music and film. His expeditions have taken him to the deep Amazon and rainforests of Thailand, Costa Rica, Guatemala, Brazil, Colombia, Indonesia, Peru, Mexico and many other places.

Chuck is the owner of the independent record label, Sonic Safari Music. He has produced and published more than 100 CDs of exotic music.

Chuck was pleased to be invited by Allan Smith to travel to Borneo to film. “Allan and I have worked on several projects together, but I was intrigued by Dusty’s Trail,” said Chuck. “I’m always influenced by those who struggle with difficult circumstances. I try to appreciate the little things and hopefully bring joy to those who suffer”.

Ben Zarai, Supervising Sound Editor, Re-Recording Mixer

Emmy Award-winner Ben Zarai began writing music at the age of seven. A native of Los Angeles, Ben grew up immersed in music and film. His love for both led him to pursue these two art forms professionally.

As a well-regarded composer, Ben has scored films starring actors such as Forest Whitaker, Bruce Willis, 50 Cent, and Val Kilmer. Ben wrote, directed, produced and edited a documentary about his work with James Cameron, which Cameron included on one of his DVDs. Ben associate-produced four feature films. He wrote two feature film scripts. And he has mixed and/or sound-designed more than two hundred feature films, making him a foremost expert at making music work in movies.

David Kitchens, Sound Supervisor

David Kitchens has an industry leading resume in sound. He has several pages of IMDb film credits and heads Juniper Post, an award winning sound studio in Burbank California. David is an Emmy award winning sound supervisor for work done on James Cameron's: Expedition Bismarck. David jokes that he has not done a serious bio since the 90s because he has been working too hard!

SCREEN SHOTS FROM DUSTY'S TRAIL













BACKGROUND ON PRESENT MOMENT YOGI PRODUCTIONS

Present Moment Yogi Productions is committed to making a difference in the world with inspirational messaging through the medium of film and documentary.

Present Moment Yogi Production's mission is to inspire and convey stories of inspiration, hope, motivation, transformation, caring, kindness, compassion, encouragement and empowerment.

Present Moment Yogi Productions nurtures compelling and uplifting stories that need to be seen and heard. Present Moment Yogi Productions is devoted to individuals on a journey through adversity. They seek projects that connect people with the world around us and illuminate just who they can be at their very best.

Catherine Jayasuriya is president and founder of Present Moment Yogi Productions.

BACKGROUND ON DUCHENNE MUSCULAR DYSTROPHY

Duchenne muscular dystrophy is a progressive muscle wasting disease. It is the most common fatal disease that affects children. Duchenne occurs in 1 in 3,500 male births, across all races, cultures and countries. It can happen to anyone.

Duchenne is caused by a defect in the gene that codes for the protein dystrophin. Dystrophin is a vital protein that helps connect the muscle fiber to the cell membranes. Without dystrophin the muscle cells become unstable, are weakened and lose their functionality.

Some of the common signs and early symptoms of Duchenne are difficulty in walking, running and climbing. By the age of 6 -7 boys start to fall often and fatigue quickly. Their calf muscles appear large because they become fibrotic. Muscle weakness occurs in the lower extremities first.

By the age of 10-12, most boys are in a wheelchair. There is a continued deterioration of the shoulders, arms and hands. During the mid teens, boys may need help with eating. It is during this time that their back muscles become too weak to support their spine which results in scoliosis. Whilst some boys have rod surgery to straighten their spines, others suffer severe scoliosis.

During the late teens, respiratory weakness occurs in the diaphragm, as muscles that operate the lungs get weaker. Boys often require breathing assistance during the day and night, such as a ventilator or a permanent tracheotomy. Assistance is needed for coughing, and respiratory infections become life threatening. The heart is also involved, and some boys develop an early onset of cardiomyopathy which can lead to heart failure.

Life expectancy varies due to complications of the heart and lung functioning, and the type of gene deletion or duplication. The rate of progression and severity is different for each boy. The general span for life expectancy ranges from the mid teenage years to the mid 20's.

There is no cure, although, in the last 10 years there have been major advances in science and in standards of care. With informed and timely treatment, some boys with Duchenne are living longer lives than ever before.

BACKGROUND ON COALITION DUCHENNE

Catherine Jayasuriya founded Coalition Duchenne in 2011. Coalition Duchenne is a non-profit organization that raises global awareness and funding to find treatments and a cure for Duchenne muscular dystrophy through donations and various annual fundraising events.

Coalition Duchenne's commitment is that one hundred percent of all money raised goes directly to fund research. The organization is opportunistic but rigorous in pursuit of research strategies. It operates with strong business principles and utilizes the latest technology and software to leverage its efforts and maximize its efficiency. Coalition Duchenne's scientific advisors are world leaders in their fields.

The founders helped in the early stage development of some of the key research that is now paying dividends for sufferers of Duchenne today. Their funding of the Dusty Brandom Fellowship at the University of Western Australia led to groundbreaking exon skipping research. They were one of the first investors in small molecule screening.

Duchenne research is advancing rapidly. Coalition Duchenne is currently pioneering funding of poloxamers and cardiac stem cells for Duchenne hearts.

The impact of Duchenne is felt across the globe, from the USA to Asia, Australia, Europe, India, South American and Africa. Duchenne knows no boundaries, and does not discriminate between race, culture, socioeconomic status or country. Coalition Duchenne is committed to making a difference in the lives of all boys and young men with Duchenne. The founder's son Dusty, is one of them.

MOVIE REVIEW

dailypilot.com/opinion/tn-dpt-0127-apodaca-20130125,0,105656.story

The Daily Pilot Newport Beach California

A documentary for Dusty

By Patrice Apodaca
January 26, 2013

Imagine for a moment that you can't walk or reach out to embrace your loved ones, and that every breath you take, each beat of your heart, requires a herculean effort from your weakening body.

That is life for my neighbor Dusty Brandom and millions of boys and young men worldwide who suffer from the incurable, muscle-wasting genetic disease Duchenne muscular dystrophy, the most common fatal genetic disorder diagnosed in children.

Readers might recall Dusty from previous columns, including one in which I wrote of his meeting with President Obama at the White House in the spring of 2011. Over the years, he has battled against the progression of

devastating symptoms that now keep him confined to a wheelchair, in need of breathing assistance, and taking his meals through a straw. At 20, he has already outlived some Duchenne victims.

Recently, Dusty's mother, Catherine Jayasuriya — Cath to friends and family — asked me to view a documentary that she coproduced, "Dusty's Trail: Summit of Borneo."

In all honesty, I wasn't sure what to expect. I knew that during the course of Dusty's illness, Cath had evolved into a fierce advocate on behalf of Duchenne victims and had founded the nonprofit organization Coalition Duchenne. Indeed, the entire Brandom family, including Dusty's dad, Neil, and younger siblings Lucas and Gabriella, has fought valiantly to shed light on Duchenne, encourage the pursuit of treatments, and ensure that Dusty has a full and meaningful life in spite of his physical limitations.

As part of that effort, Cath recruited 62 participants from around the world last August to climb to the 13,435-foot summit of Mount Kinabalu in Malaysian Borneo. A native of Malaysia, Cath spearheaded the expedition — the second of its kind — to raise awareness about Duchenne.

She didn't stop there. Cath also founded a production company, Present Moment Yogi Productions, and hired an award-winning film crew to record the event. Back in Newport Beach, the production team continued work on the documentary, which weaves together the story of the climb with background on Dusty and Duchenne.

When I arrived at the Brandom's home, I was introduced to Mindy Cameron, who appears in the film. Mindy also lives in Newport Beach and has an 11-year-old son with Duchenne. Also on hand were one of the filmmakers, Andrew Fink, who was about to make the final editing touches, and Dusty, who was seeing the film from start to finish for the first time.

As we sat down to watch, Cath placed a box of tissues in close reach. I don't mind sharing that it was needed.

What Cath and her team have created is a beautiful, heartbreaking, yet also wonderfully uplifting film. Without resorting to an overt play for sympathy or manufactured pathos, they tell their story simply and directly, with gorgeously rendered photography and editing, and sometimes wrenching testimony. That the documentary is at once poignant and hopeful reflects the care that went into its making.

The opening shots, set to music, provide a fitting introduction. They show feet walking, legs jumping and arms hugging — the types of everyday activities that most of us take for granted, but which become impossible for Duchenne victims.

The film offers expert testimony about the cause, symptoms and prevalence of Duchenne, and interviews with many people who have been touched by the disease, including one mother who lost two sons to Duchenne, and who now also advocates for effective treatments.

A few scenes were particularly powerful. In one, Cath is seen visiting a Malaysian family that couldn't afford a wheelchair for their son with Duchenne. Another segment provided a welcome spark of humor when a young man with Duchenne quipped that people treated him like Jesus because he had reached the seemingly miraculous age of 32.

Some of the most moving scenes appeared near the end of the film, with footage of climbers reaching the summit of Mount Kinabalu interwoven with those showing Dusty during a medical exam; at one point, an image of his heart shows clearly on a monitor.

In spite of all the tissues I destroyed, "Dusty's Trail" — like Dusty himself — remains inspiring and optimistic. The message is clear: Treatments to improve the quality of life of Duchenne sufferers, even one day an outright cure, are possible.

In a speech before embarking on the Mount Kinabalu expedition, Cath reminded her fellow climbers that they were there for the "boys who face a far greater challenge than any mountain peak."

I glanced over at Dusty as we finished watching the film, and saw his radiant, ever-present smile. His challenges are great indeed, but they are met with uncommon grace and strong intent to savor every moment of joy that can be had in life as it is.

PATRICE APODACA is a Newport-Mesa public school parent and former Los Angeles Times staff writer. She is also a regular contributor to Orange Coast magazine. She lives in Newport Beach.

MOVIE REVIEW

http://articles.dailypilot.com/2013-02-28/entertainment/tn-dpt-0301-reel-critics-20130228_1_political-thriller-chile-ad-campaign

The Daily Pilot Newport Beach California

Reel Critics: A rugged and inspiring 'Trail'

By John Depko

February 28, 2013

I was privileged to attend the private screening of a captivating new documentary. Catherine Jayasuriya is a very sharp local mom on a major mission. She is the driving force behind "Dusty's Trail," which is vying for a spot in the Newport Beach Film Festival.

Dusty is Catherine's handsome 20-year-old son, who is wheelchair-bound. He has Duchenne muscular dystrophy, a genetic disease that Catherine is determined to help conquer. She set up a charity to increase awareness of the affliction and raise money for medical research.

Catherine organizes a yearly fundraising trek of supporters to hike the trails of Mt. Kinabalu in her ancestral home in Borneo. The film features stunning footage of their climb up the mountain's famous alpine meadow ecosystem. These beautiful scenes are intertwined with pointed interviews with doctors, patients and researchers working to cure the disease.

The story packs a lot of intelligence and information into a crisp running time of 65 minutes. Joy, hope and tears get equal time on screen. Credit cameraman and film editor Andrew Fink with a top-notch job. He combines all the right scenes with dynamic, uplifting music to stir the mind and heart to Dusty's cause.

For more info, visit <http://www.dustystrail.com>.