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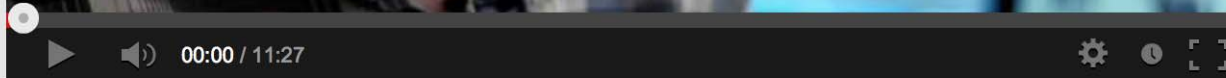
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My PKU Life

by creativecontrolfilms 1 year ago

20,046 views



About Creative Control Films

Edit

We produce documentaries, short films, branded entertainment, corporate films, and TV/Web/Cinema promos.

Our President, Kevin Alexander, is also an advocate for newborn screening & the rare genetic disease PKU. He is the host of Patient Power's P...

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- Creative Control Films
- Twitter
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- PKULife.tv
- PKU Advocate Kevin Alexander

by creativecontrolfilms

Date Joined Sep 20, 2011

Country United States



PKULife.tv PRESENTS
FOR KATY
Produced & Directed by
Kevin Alexander
NOW AVAILABLE | **PKULife.tv**



New short film about rare disease PKU



Short Film: For Katy

3 weeks ago



My PKU Life

1 year ago

NEWEST VIDEOS



Short Film: For Katy

Added by Kevin Alexander 3 weeks ago

132 Views 0 Comments 0 Likes

Katy is seven years old and has Phenylketonuria (PKU), a rare genetic disease in which the body cannot metabolize protein properly. Many in the world who are born with PKU are diagnosed at birth because of newborn scr...

RECENT POSTS

- Short Film: For Katy
- Raising Awareness about Newborn Screening & PKU in Brazil
- 50 Year Celebration of Newborn Screening Affirms Life-Saving Efforts
- New Care Guidelines a Key Focus at the 2012 European PKU Conference
- Research Update: PKU and the Brain

RECENT COMMENTS

- Kevin Alexander on My PKU Life
- Olive Hunt on My PKU Life
- Kevin Alexander on My PKU Life
- Alley on My PKU Life

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Thanks to Adobe & Pond5.com for ...	231	--	Boost Post
I rarely say this, but this article is a...	234	--	Boost Post

Messages

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- Ali Ramez Hasan**
You're welcome!
- Erin Syverson**
Hello! I messaged you earlier this ye...
- Amy Kunstmann**
Thank you so much. Also, this eveni...
- Seema Ahmed**
I'm not sure... It hasn't been aroun...
- Christopher Howell**
Thanks man... It means a lot 😊

New Likes

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- Jessica Lorefice**
50 minutes ago
- Corina Girleanu**
on Tuesday
- Elaine Grönkvist-Olsson**
on Monday
- Patricia Ann Kaune**
on Sunday

Insights

See All



Invite Friends

- Pku Survivor Moya Chappell** Invite
- Elizabeth Rogers** Invite
- Teri Hermann Metcalf** Invite
- Teresa Landers Verdahl** Invite

Now

2013

Joined Facebook



PKU Advocate Kevin Alexander

648 likes · 182 talking about this



Public Figure

I'm 32 and have PKU. In November 2011 I produced a short documentary "My PKU Life". I have since become an advocate for PKU and newborn screening. My latest short film, "For Katy", is available on my website: www.pkulife.tv.

About



Photos

648

Likes

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PKU Advocate Kevin Alexander



I'm 32 and have PKU. In November 2011 I produced a short documentary "My PKU Life". I have since bec...

Like · PKU Advocate Kevin Alexander likes this.

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	Post	Total Reach?	Paid Reach?	Promotion		
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	I rarely say this, but this article is a...	234	--	Boost Post		Christopher Howell ← Thanks man... It means a lot 😊
New Likes See All		Insights See All			Invite Friends	
	Jessica Lorefice 50 minutes ago	<p> ■ Talking About This ■ Reach </p>				Pku Survivor Moya Chappell Invite ×
	Corina Gîrleanu on Tuesday					Elizabeth Rogers Invite ×
	Elaine Grönkvist-Olsson on Monday					Teri Hermann Metcalf Invite ×
	Patricia Ann Kaune on Sunday					Teresa Landers Verdahl Invite ×

Status Photo / Video Offer, Event +

What's happening?



PKU Advocate Kevin Alexander

19 hours ago

Good to know the 4 PKU families in the Moore, OK area are doing OK, and haven't lost formula or low-pro food. It's also pretty cool to see so many in the PKU community across the world express so much concern for those 4 families. We may not be a large community, but we certainly are a tight-knit group. (By the way, if you're not part of the PKU Worldwide Support group here on FB I highly recommend it!)



Phenylketonuria (PKU) World Wide Support Group!

I just spoke with Mary E. Monks, RN, Metabolic Nurse Specialist, Newborn Screening Metabolic Long-Term Follow-Up Coordinator with the Oklahoma Dept. of Health, their staff Dietician has been in contact with the 4 PKU families they are currently aware of in the Moore, OK...

Like · Comment · Share

1



Ali Ramez Hasan, Jessy Widmer, Margueritte Phelps Bruno and 5 others like this.



Write a comment...



Anthea Gawler It warms my heart to see so much caring you are the most wonderful people.

Like · Reply · 10 hours ago

267 people saw this post

Recent Posts by Others on PKU Advocate Kevin Alexander See All



Margueritte Phelps Bruno

Since many of you have kids with PKU, just wanted ...

1 · 1 · May 14 at 2:35am



Michelle Moffett Francis

PKU Advocate Kevin Alexander is a talented videogr...

2 · 1 · May 8 at 2:37pm



Caren Pearson

hi just wanted to say love the work your doing i am m...

1 · 4 · May 8 at 7:46am



Lillian Jenkins

My PKU Life is AWESOME!! Enjoyed meeting you today.

1 · 1 · May 7 at 9:19pm



Karey Hudson Padding

I enjoyed meeting you today and participating on the ...

1 · 1 · May 7 at 9:15pm

More Posts

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VitaFlo VitaFriends

Health/Medical/Pharmaceuticals



Random Acts

Non-Profit Organization



Casey Ryan - The Cutting Room Floor

Public Figure



Adobe

Product/Service



Camp PHEver

Non-Profit Organization





Tag

+ Add Photos Edit *

Curitiba, Brazil

Updated about 4 months ago

Speaking at a Newborn Screening Symposium



Like · Comment · Share

1

Alvera Bruwer, Adriana Marchesin, Yuliya Dorofeeva Geary and 11 others like this.



Write a comment...



PKU Advocate Kevin Alexander

December 12, 2012

Newborn screening workers from Curitiba watching "My PKU Life"

Tag Photo

Add Location

Edit

Like · Comment · Share · Edit

Mara Alexander likes this.



Write a comment...



PKU Advocate Kevin Alexander

December 12, 2012

Two new friends, Vere & her son Frederico who has PKU.

Tag Photo

Add Location

Edit

Like · Comment · Share · Edit

Mercedes Rose-Marie Sabev, Donalda MacLellan and Mara Alexander like this.



Write a comment...




PKU Advocate Kevin Alexander
December 12, 2012

A BIG thanks to my interpreters!

[Tag Photo](#) [Add Location](#) [Edit](#)

Like · Comment · Share · Edit

Elisa B. Skidmore and Mara Alexander like this.

 Write a comment...





 **PKU Advocate Kevin Alexander**
July 28, 2012

Meet my new buddy and fellow PKUer Zachary Raitz!

[Tag Photo](#) [Add Location](#) [Edit](#)

[Like](#) · [Comment](#) · [Share](#) · [Edit](#)

 **Amy Packer Wakeland, Crook Shanks, Mary Sam Stoddard and 38 others like this.**

 2 shares

 **Lorraine Muller** Wow! a handsome young man, with his hat and cool shirt.
July 28, 2012 at 9:18pm · [Unlike](#) · [1](#)

 **Jason Raitz** Thanks again Kevin! He loved it!
July 28, 2012 at 9:20pm · [Unlike](#) · [1](#)

 **Zoe Mitter** If you come to Australia you can come and meet my little PKUer - Cayden Mitter. You are doing awesome things Kevin. Congratulations!
July 29, 2012 at 1:14am · [Like](#)

 Write a comment...





PKU Advocate Kevin Alexander

October 9, 2012

A group of kids at a PKU camp hosted by PKU Association of NSW in Australia. They watched a personalized greeting I recorded for them to introduce My PKU Life.

Tag Photo

Add Location

Edit

Like · Comment · Share · Edit

Samantha Hammond, Patient Power PKU, Natasha Bramwell and 22 others like this.

1 share



Margueritte Phelps Bruno Whenever this picture pops up on my screen, I keep thinking it'd be nice to be able to push "play" ...
October 10, 2012 at 3:59pm · Like



PKU Advocate Kevin Alexander Maybe I'll post it to YouTube 😊
October 10, 2012 at 4:10pm · Like · 1



Write a comment...



PKU Advocate Kevin Alexander

August 23, 2012

A few weeks ago I sent an email to Senator Mary Landrieu's office advocating for PKU. Her office sent a

[Tag Photo](#) [Add Location](#) [Edit](#)

[Like](#) · [Comment](#) · [Share](#) · [Edit](#)

Cristina Hernandez, Eileen Parker and 6 others like this.



OFFICE OF THE MAYOR
SHREVEPORT, LOUISIANA

CEDRIC B. GLOVER
MAYOR

POST OFFICE BOX 31109
SHREVEPORT, LA 71130
(318) 673-5050 / (318) 673-5099 (FAX)

PROCLAMATION

WHEREAS, the United States Senate has designated December 3, 2012, as National PKU Awareness Day; and

WHEREAS, Phenylketonuria is a rare inherited metabolic disorder that affects the way the body processes food into energy; and

WHEREAS, there is no cure for PKU, emerging treatments with drugs and dietary management are still the mainstays of therapy; and

WHEREAS, the City of Shreveport seeks to raise awareness of this rare disorder and offer encouragement to those suffering with PKU as well those committed to finding relief for their loved ones;

NOW, THEREFORE, I, CEDRIC B. GLOVER, MAYOR of the City of Shreveport, do hereby proclaim Monday, December 3rd, 2012, as:

“PKU AWARENESS DAY”

In the City of Shreveport, and urge all citizens to help raise awareness of this disorder and support for those seeking a cure.

IN WITNESS WHEREOF, I have hereunto set my hand and caused the Seal of the City of Shreveport to be affixed.



A handwritten signature in black ink, appearing to read "C. B. Glover".

CEDRIC B. GLOVER
MAYOR





PKU Advocate Kevin Alexander shared a link.

May 2 near Shreveport 🌐



I am pleased to announce that my latest short film, "For Katy", is now available for purchase at Vimeo.com.

Katy is seven years old and has Phenylketonuria (PKU), a rare genetic disease in which the body cannot metabolize protein properly.... [See More](#)



For Katy

Katy is seven years old and has Phenylketonuria (PKU), a rare genetic disease in which the body cannot metabolize protein properly. Many in the world who are born...

Like · Comment · Share

🗨️ 25

👍 Lena Kiger, Amy Newby, Monique Hatton Slaughter and 12 others like this.



Write a comment...



PKU Advocate Kevin Alexander Thanks for watching 😊

Like · Reply · 👍 1 · May 2 at 5:32pm



PKU Advocate Kevin Alexander Thanks Frank!

Like · Reply · May 2 at 1:27pm

🗨️ View 3 more comments

1,990 people saw this post

Boost Post ▼



PKU Advocate Kevin Alexander

May 2



This makes my heart very happy. Sony Professional USA (their broadcast professional page) has been very encouraging in all of my PKU & newborn screening advocacy efforts. Sony, I truly appreciate all the retweets and shares of my work. It's obviously satisfying on a personal and professional level, but it also means SO much to our community!



Sony Professional US @SonyProUSA

1m

RT @KevCCFilms: @SonyProUSA My latest short film about #PKU, now available at bit.ly/11Evpa0 | Shot exclusively w/ #FS100.

[Hide media](#) [Reply](#) [Retweeted](#) [Favorite](#) [More](#)



For Katy

Katy is seven years old and has Phenylketonuria (PKU), a rare genetic disease in which the body cannot metabolize protein properly. Many in the world who are born...

[View on web](#)

1 RETWEET



Like · Comment · Share



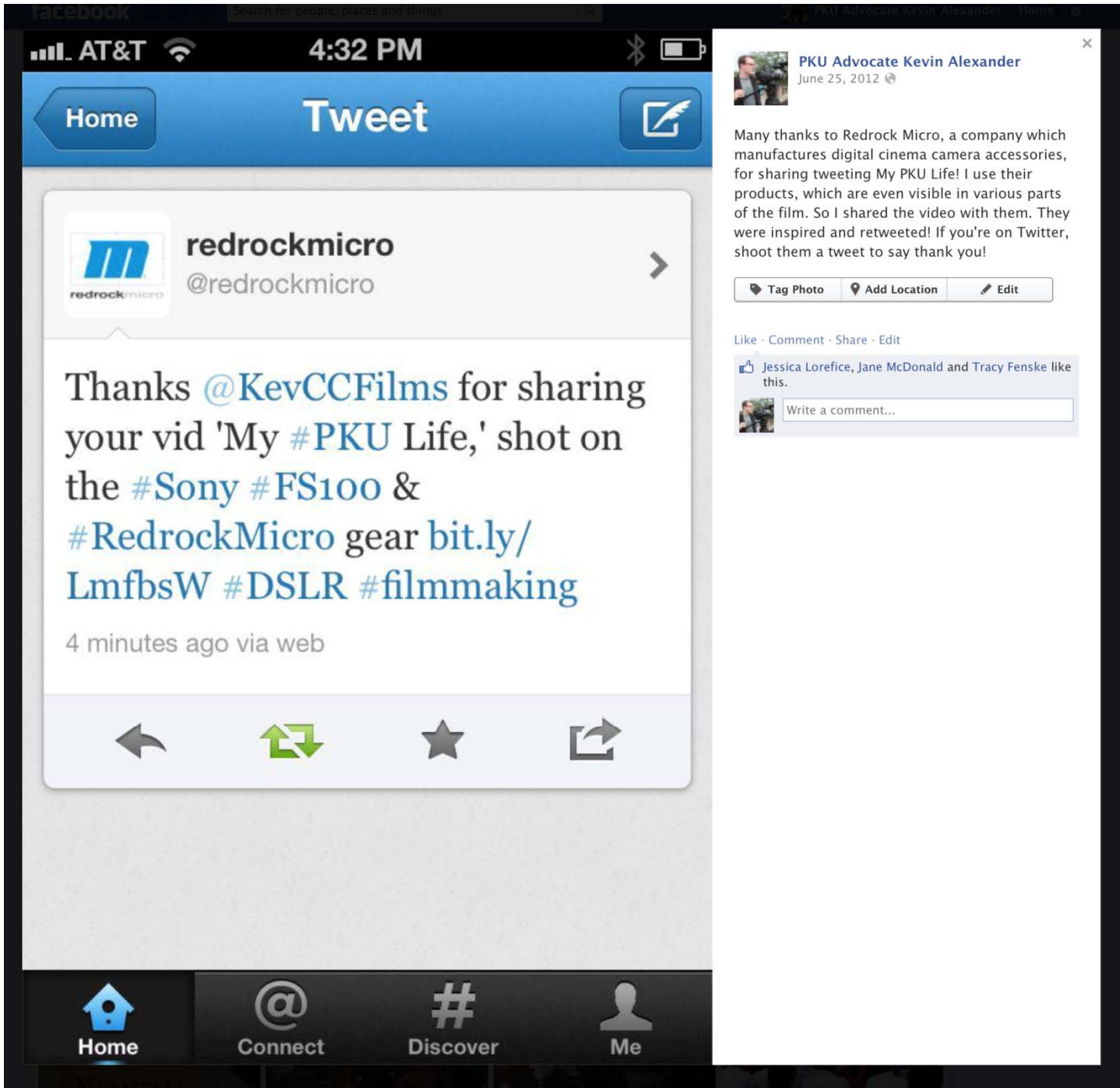
Mara Alexander, Jackie Lauber, Debbie Burns and 14 others like this.



Write a comment...

511 people saw this post

Boost Post



redrockmicro @redrockmicro

Thanks @KevCCFilms for sharing your vid 'My #PKU Life,' shot on the #Sony #FS100 & #RedrockMicro gear bit.ly/LmfbsW #DSLR #filmmaking

4 minutes ago via web



PKU Advocate Kevin Alexander June 25, 2012

Many thanks to Redrock Micro, a company which manufactures digital cinema camera accessories, for sharing tweeting My PKU Life! I use their products, which are even visible in various parts of the film. So I shared the video with them. They were inspired and retweeted! If you're on Twitter, shoot them a tweet to say thank you!

Tag Photo Add Location Edit

Like Comment Share Edit

Jessica Lorefice, Jane McDonald and Tracy Fenske like this.

Write a comment...