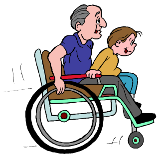

Special Edition I

August 2010

ECD GLOBAL ALLIANCE NEWS

ECD Global Alliance News

WHO IS THE ECD GLOBAL ALLIANCE?

This special edition of the ECD Newsletter is dedicated to all those affected by ECD – in memory of those who lost the battle, in honor of those battling a diagnosis, the friends and loved ones supporting them, and the friends and loved ones left behind. If you have been affected in any way by ECD, *you* are the ECD Global Alliance. This is *your* organization. We exist because of *you*!

Simon*
&
Joanna

Kristine and Walter*

Rita* & Sailor

"Erdheim Chester Disease affects Tanya's body but by the grace of God our lives abound with opportunity and together we look forward and out and we find that the world is a bright and beautiful place to be alive."

Charles and Tanya*

FROM THE EDITOR

As the wife and caregiver of an ECD patient I know the trials of dealing with such a rare disease. It is the reason I volunteer my time to publish and edit the newsletter. Being a member of the ECD Global Alliance community has given me a sense of belonging I do not feel anywhere else. When I first decided to publish a special edition of the ECD Newsletter containing pictures of our members, I thought it would be an easy task. But as the pictures started coming in, and people began sharing their stories, I found myself deeply affected by each email. Although we are all different in many ways, we are walking a similar path dealing with a very rare disease. We can relate to the frustrations, the trials, and the triumphs.

(Continued on page 3)

Steve*, Rita, Ally, Taylor Bruno

Sharon* and Don

(Continued from page 2)

I try my best but it is not always easy to be positive. There are days when I wonder how much more of this we can take…how much more will we have to endure? Even though I do not have ECD, I still suffer because the love of my life suffers. Days turn into weeks…weeks turn into months…and months turn into years. We watch as everyone around us lives their life, while life seems to stand still for us and everything blurs together as we continue to adapt to our "new normal" with each progression of the disease. It is difficult to explain it to somebody who has not walked a similar path. My circle of friends gets smaller with each passing day. I have gone through stages of denial, anger, frustration, bitterness, etc. After all, we have been dealing with this since we were in our mid-20's – a diagnosis of histiocytosis just 15 months after we were married.

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Dale* "Bardbird"
and
Barbara

Annalee
and
Bryan* "Jiggs"

"Best advice - never say never: never give up: lean on your faith: share with your loved ones and others (you never know who can help) Physicians are only as good as their skills and knowledge allows; the pharmaceutical companies are not your friends (they provide tools for our use, but are driven by $) join support groups like our chat line."

Mike* and Carol

(Continued from page 3)

But even though this journey has been difficult, I would not trade the life we have had. We truly have much to be thankful for, and ECD has made us appreciate the smaller things in life. I never fully understood the phrase "Take time to stop and smell the roses" until dealing with this disease became almost unbearable. It was then that I realized I had a choice to make – I could either let ECD consume me, or I could make the most of each and every day. I try to choose the latter, but some days it is just not that simple! But the days when I *am* able to make the most of our situation I feel so much joy, hope, and peace.

(Continued on page 5)

RuthAnn "YankeesFan" and Lance*

"Never before have I met doctors who say – 'Mmh, I have never seen that before', which does not fill you with confidence. However with the help of various specialists I may be able to return to a normal life, whatever that means."

Stephen*

Larry*

(Continued from page 4)

Thank you to everyone who submitted photographs for this newsletter, and to all of you who continue to reach out to those affected by ECD. I do not know where we would all be without each other!

Peace and Blessings~

RuthAnn (YankeesFan)

Mark Jr., Sonya, Mark Sr., Christine Cassandra, Christiana* "Kit"

"Kit"

Richard

*Kathy and Gary**

*Gary**

In Loving Memory of Gary, Jim, and Gary

*Jackie and Jim**

What can a donation provide?

You may think it is not worth making a donation if you are only able to send a few dollars, but every dollar counts. Below are just a few examples of what a donation can do for all those affected by ECD:

- $10 – Host website for one month
- $25 – Host Board of Directors teleconference
- $40 – Host Medical Advisory Board teleconference
- $100 – Host the website (www.erdheim-chester.org) for one year
- $150 – Print flyers and posters for a fundraising event
- $150 – Pay NORD membership dues for one year
- $240 – Host a year's worth of Advisory Board teleconferences
- $300 – Host a year's worth of Board of Directors teleconferences
- $900 – Pay ECD Global Alliance insurance for one year
- $1500 –Pay for an IRB review to develop an ECD Registry
- $4,200 – Fund one month of a year long ECD specific research project
- $50,000 – Fund an ECD specific research project for one year
- $100,000 – Fund an NIH fellow at NIH for 1 year
- $300,000 – Fund an NIH fellow at NIH for 3 years

Did you know that all the positions held in the ECD Global Alliance non-profit organization are 100% volunteer? These people selflessly dedicate their time (some even spend their own money) to help everyone who has been affected by ECD, in the hopes of someday finding a cure. The money you donate does not go towards salaries or travel. And we are the only organization dedicated solely to Erdheim-Chester Disease, so you can be assured that any money donated to the ECD Global Alliance will go towards finding more focused and effective treatments for ECD.

Please mail your tax deductible donations to:

The ECD Global Alliance
c/o Ralph Stallard, Treasurer
6375 Thomas Jefferson Hwy
Charlotte Courthouse VA 23923 USA

Or make a donation online:

http://www.razoo.com/story/Ecd-Global-Alliance

A special thanks to our webmaster, Nick, who selflessly dedicates his time to the ECD Global Alliance. Although he has not been personally affected by ECD, he became involved with the organization because he enjoys the work and the feeling that he is helping others. As a friend of Kathy's (GarysKat) when he heard about our plans for the organization he was one of the first to volunteer . He currently resides in Greece.

Thank you, Nick, for all that you do for us! We appreciate you!!!

If you have any comments or would like to submit an article for a future newsletter please email the editor at stanceforlance@hotmail.com. Feedback and input is always welcome. Together we are making a difference!