FROM THE EDITOR

The start of 2020 sure has been unbelievably challenging for our world and ALL of our FOD Families! I hope wellness, kindness, peace and love can help change our world for the better!

As I stated in the Jan 2020 Newsletter, changes are also coming to the FOD Group. Since we are no longer having large Conferences every 2 years, we still hope to have our 1st FOD Regional MeetUp in conjunction with the Rare New England (RNE) Conference on Oct 24th in Hartford, CT. However, the RNE has made the decision to make this a virtual conference, so I will post info as soon as I receive it in both the facebook and google Groups when the Registration Form is on the RNE website.

Another addition to our website, is our new FOD Welcome Kit for New Families. THANK YOU to Rosemary Forrest (CPT 2 grandma and medical writer) for helping with the writing of the information! We hope it'll help Families get a better understanding of the FODs and for finding further resources for support and networking.

We also may be making changes to our Newsletter ~ with everything already online and/or posted in our facebook and google Groups, we may forgo an actual Newsletter and just post Family Stories, Medical Info etc on our website on those specific pages because there has also been a lack of interest in members sending me Stories and other submissions. I am still exploring this option. Until then, think about submitting for Jan 2021 ~ deadline is Dec15, 2020!

In the meantime, help create Awareness around the world by promoting and sharing your Family Stories with everyone willing to listen. Please also share our 2020 FOD Awareness Banner (as posted in our facebook groups a jpeg pic and on page 9) on your social media sites. Another way to create awareness is to purchase some of our Awareness Items and wear them with Pride! Also when you shop amazon be sure to bookmark and shop every time from our FOD amazonsmile link ~ we benefit from all of your purchases ALL year round by earning a certain percentage of your total purchase! Online and check Donations directly made to the FOD Group are tax-deductible.

Always remember ~ Whether you’re a Family or a Professional, we are all striving to create more awareness, education, screening and diagnosis, long-term clinical treatment, and research ~ by sharing your story or your expertise…

“We are All in This Together’'

Take care… Deb Lee Gould, MEd, Director

‘All in This Together’
**EDITORIAL**

With all that is going on in the world right now, we as a Group want you to know that we welcome ALL Families around the globe living with an FOD. And that can be at the very beginning of your journey after a positive newborn screen or after many years of living with the FOD.

We want our Families to feel supported and have an avenue to share their challenges, fears and experiences as parents, affected teens and adults, or other family members that want to learn more in order to be there for their loved ones.

One way that we are expanding our Group Outreach is by offering zoom Chats!

We have already had a few zoom chats for specific FODs, so be on the lookout for more morning and afternoon (est) times. There will be a link to Register for them so I know how many to expect. If we get larger numbers I will divide the chat into breakout rooms. It’s a wonderful way to network and offer support and wisdom to any person living in this ‘rare’ world!

~ DLG
Kelli’s Story ~ VLCAD

Dancing Through Life Despite Diagnosis

[printed in Baton Rouge Parents]

The day after Kelli Guillory was born, she stopped breathing twice. The code blues were terrifying experiences for her mother, Jennifer Guillory. But the medical professionals weren’t sure why baby Kelli was having trouble.

It wasn’t until Kelli was out of intensive care and following up with their pediatrician that Jennifer finally heard of very-long-chain acyl-CoA dehydrogenase deficiency (VLCAD, pronounced V-L cad), the condition with which Kelli, who turns 11 this month, is living.

Because of the rare genetically inherited disease, Kelli’s body is unable to break down certain fats. “For us, our food sticks to us and turns to energy,” Jennifer says. “For her, it doesn’t. It burns right through her.” So Kelli must stick to a strict high carb diet with less than 20 percent of fats per day. A fourth grader at Parkview Elementary, she has extra snacks built into her days at school, and any time she’s more active, she must also eat more.

For any type of vomiting or diarrhea, both typical childhood illnesses, Kelli has to go to the hospital and emergency protocol must be followed. “If they don’t, it can leave her with brain damage or kill her,” Jennifer says. “She’s been hospitalized 71 times.”

It has only been a year since Kelli has been in the hospital, making it only the second time in her life that she has gone that long without an admission to the hospital. “Sometimes when I was little, I used to call the hospital my second home because I had been there so many times,” Kelli says.

Kelli also has hemolytic anemia; her red blood cells are destroyed faster than they can be made. But the exact cause of that problem is unknown. “Everything they’ve tested her for (at St. Jude Children’s Research Hospital), it’s come back negative,” Jennifer explains. “She has been my fighter since birth.”

Because of the frequent hospital visits, Kelli has had a port implanted since her first year of life. It makes IV medication much easier to administer, and it must be flushed monthly. Kelli is a pro at managing those parts of her care.

“She could check her blood sugar at three years old by herself,” Jennifer says. “In the hospital, she would help the nurses flush her ports.”

Kelli leads a full life while managing VLCAD. She’s active in her Girl Scout troop and part of the Healing Place Church kids program. Kelli loves dancing and singing and says her top favorite thing is crafting. She has two younger brothers, David and Gary.

Giving back is a passion for Kelli, and she’s involved in raising money for the new Our Lady of the Lake Children’s Hospital through an annual dance marathon at LSU and a toy drive for children in the hospital during the holidays. She participates in radiothons for Dreams Come True, a local nonprofit that grants wishes for Louisiana children facing life-threatening diseases. Kelli was able to go to Disney World when she was six thanks to the program.

“Sometimes I don’t like having VLCAD, and sometimes I’m frustrated about it,” Kelli says. “Sometimes it aggravates me taking so much medicine.” Kelli has two penpals who also have VLCAD, and being connected with others who understand helps.
Medical & Research Update

Professionals: Please contact Deb if you’d like to write an article/summary for our next January or July issue. Our Families are really interested in learning what research and/or clinical issues you are working on!

Research Survey for rare disease patients and their families about impacts of COVID-19

Rare disease patients or their caregivers are invited to complete a 20-minute online survey from home about the ways the novel coronavirus pandemic is impacting people with rare diseases and their families.

Impacts can be related to physical health, emotional health, availability of supplies, access to care, or other problems. Your responses may help researchers understand the impacts of COVID-19 on the rare disease community.

The Rare Diseases Clinical Research Network (RDCRN) is conducting this study. The network is funded by the National Institutes of Health. It includes 23 research teams working to advance diagnosis and treatment of groups of rare diseases.

For Patient Advocacy Groups: FOD support working with the International Network for Fatty Acid Oxidation Disorders Research and Management (INFORM)

For Consortia: INFORM is one of the teams working with the RDCRN.

To complete the survey or learn more, visit the study page here. Questions? Email the study team at rd.covid19@cchmc.org.

Open until JULY 31!
New Community Survey Findings from NORD Reveal Significant Impact of COVID-19 on Americans Living with Rare Diseases

[From NORD post on May 5, 2020]

95% of respondents report being impacted to the detriment of their immediate and long-term health and well-being; 98% report being gravely worried about COVID-19.

Washington, DC, May 5, 2020—Today, the National Organization for Rare Disorders (NORD®) released the findings of its recent survey on the critical issues and concerns the rare disease community is facing due to the COVID-19 pandemic. The COVID-19 Community Survey Report is published through RareInsights™, a NORD initiative to expand public knowledge of rare diseases and translate that knowledge into real-world solutions for patients and families.

In the United States, over 25 million patients and families who are impacted by rare diseases are now managing consequential challenges brought on by the novel coronavirus. People with underlying health conditions face not only more severe illness, but rare patients, caregivers and family members are experiencing other considerable life disruptions—including financial instability, canceled medical appointments, concerns regarding drug shortages and other important issues. With a goal of shining a light on these issues and in order to best provide supportive resources that address their top concerns, NORD reached out to the rare community directly.

The COVID-19 Community Survey Report reveals the far-reaching impact the pandemic is having on rare patients and families. The findings reflect a community directly affected and overwhelmingly concerned about the COVID-19 crisis.

- 95% of respondents have been impacted at a cost to their immediate and long-term health and well-being
- 98% are worried about COVID-19; of those, 67% are very or extremely worried
- 74% have had a medical appointment canceled; of those, 65% were offered an alternative appointment via telephone or video
- 69% of respondents are concerned about medication and medical supply shortages

772 participants responded to the survey conducted by NORD's research team from April 1 through April 8, 2020. Respondents represent 49 of 50 states and Washington, DC, and multiple disease categories, including genetic conditions, primary immunodeficiencies, neurological, blood, metabolic, movement, eye, skin and other types of rare disorders.

“Through the information generously shared with us by survey participants, we are able to better understand the specific concerns and impact of COVID-19 on the rare community,” said Vanessa Boulanger, NORD’s Director of Research. “This knowledge helps us to provide the support and services most needed by our community during this challenging time.”

A follow-up survey is being planned to further monitor the experiences of patients and families as the pandemic continues. NORD is listening and will continue to channel the community’s collective voice into action, using information such as this survey data to help apprise policymakers on the challenges members of the rare community are facing and to shape our own programs and services.

As part of its response to the evolving COVID-19 situation, NORD’s policy team has been working to protect access to necessary medical treatment including telemedicine, home infusions and medication refills. NORD is also continuing to advocate to the Department of Health and Human Services and state health departments to ensure rare disease patients are not discriminated against during COVID-19 triaging.

NORD has developed the growing COVID-19 Resource Center, providing materials created by NORD as well as information from vetted sources to help educate and empower people living with rare diseases during this time. Also available is the NORD COVID-19 Critical Relief Program, which provides assistance with non-medical essential needs to eligible rare disease patients. Donations to the program are currently being accepted.

Be sure to read the COVID-19 Community Survey Report, available for download here.
Get paid for your opinion and benefit the FOD Group at the same time. Patients (14 and older) and Caregivers (family, friends) of any disability, disorder, syndrome, disease or condition are provided an opportunity to voice their opinions through surveys and interviews to improve medical products and services.

Join the community on-line and We receive $5 for each qualified signup. Refer others and we will benefit each time. Your information is confidential, and your email/name is never shared. You may be invited to participate in surveys from time to time, where you will earn cash. Click below and JOIN!

Why Sign up with Rare Patient Voice?
Who knows better than you about your journey and experiences? We connect you with researchers who are developing products and services which can help you and others with your condition. These researchers need patient input so that they develop products and services that have a meaningful impact on patients’ lives. Over the past seven years, Rare Patient Voice has paid patients over $4.8 million dollars.

How will I be paid?
You will earn $100 per hour for participating in studies. We pay by check to ensure patients can use their compensation in any way they wish.

Sign Up Today!
http://rarepatientvoice.com/fattyoxidationdisorders

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Info & Articles of Medical Interest & Resources

What is a rare disease? It’s not as simple as it sounds

Gene Cards: The Human Gene Database
**REACH FOR THE STARS**

**Congratulations** to Olivia Krafft. Today she would have walked in her commencements but that has been postponed until August due to the virus. Olivia overcame some major health issues to earn this degree. She worked so hard!!! I’m proud beyond words. Now on to her adult job at the technical center campus of Comerica Bank where she will be working in all forms of software development.

Proud mom **Melissa Stefani-Krafft**

[Image of Olivia Krafft with a graduation certificate]

Here is Melody, now age 12, VLCADD. It's been a really rough journey at times, but she is now "en pointe" in ballet. We are about to enter summer, which is really tough on her here in California, and she's an adolescent, so our "golden years" between age five and now are over, but we're hopeful that she can continue dancing with modification. Melody LOVES dancing. She’s still drawing and writing, but now focused almost exclusively on poetry. She doesn't like drawing attention to her VLCADD, but I'm hopeful she will agree to the poem. We lost our home (and neighborhood, and practically entire town) in a wildfire in November 2018, and she wrote a poem about that, which she allowed others to see, so maybe she will write one for her FOD family.

mom, **HeatherRae Sprague**
Poems & Art by Melody Snow

'The Fanged Season'

Summer is like a scorpion.
Summer is everywhere
But here is torture.
Summer is a fanged season;
It pierces spring’s earthy heart
Until all the flowers die.
Summer is a bad time
To be a rare being.
A bad time to be outside,
To be in the sunshine.
Summer silent killer.
Summer sapphire heat.
Summer singing the song of
pain.
Summer kills both plants and
rain.
There is no ocean where I live.
I have no swimming pool.
The lake is near, that is true,
But having a boat would be
cool.
I don’t like the sun.
I don’t like the heat waves.
I don’t like summer.
All the flowers die.
No clouds in the sky.
No ocean near me.
No pool, no stream, no sea.
Only a murky lake
But while summer is still awake.
The sun will not sleep
Leaving all the water deep
In a place that’s very hot,
Like all the flowers in the
flowering pot,
Everything’s dead just like the
rain and snow.
Not a single breeze can blow.

Melody Snow

‘Winter Song’

The clouds are crying
Tears from above.
As loud as a pair
Of mockingbirds in love.
Loud and louder
Comes the rain
Writhing as terribly
As being thrashed with a chain.
Wind and lightning
Collide like a feud
Between water and air-
A black mass, a stormy mood.
It lasts a longest time-
And such a romantic
landscape it presents:
The meeting of land and
tempest.
As the rain begins to break in
segments
Until just a flourish of rain
Carried by many a rogue
breeze
Flies off a wet something-
Maybe a rose or clump of
trees.
And then there is that
enchanting moment
When all you hear is the
mockingbird
Calling for its soulmate
That the storm mimicked and
understood.

Melody Snow
I had the opportunity to represent patients with Fatty Acid Oxidation Disorders at a conference for dietitians and doctors at the end of April. Because of the pandemic it was turned into a webinar! I was able to pre-record my segment of the presentation and I talked about what it’s like to live with an FOD and a little bit about my journey with LCHAD. I am so glad doctors and dietitians get to see this webinar and gain knowledge for patients with FOD disorders!

Alex Salser, teen LCHAD
alexandra.lchadal@gmail.com

[Note from Deb: THANK YOU Alex for advocating and sharing your FOD information and wisdom!]

Rachel Vanni • Podcast Host
https://www.gooddaysbaddays.show/

A #griefpodcast about how to live your best life even when #grief smacks you in the face.

✨ Hosted by
a #widow and #grievingmom with dark humor.

linktr.ee/GoodDaysBadDays
Welcome to **FOD Awareness Month in July 2020**! We are ALL hopefully still promoting and sharing all that we know about Fatty Oxidation Disorders around the world! You can help in this effort by sharing your Family Stories with your family and friends, as well as co-workers, professionals and everyone else that is willing to listen. Please also share our **2020 Banner** on your social media sites. We are honoring Charlie, GA2/MADD (forever 3 ½ yrs old, California) and Carter, MCAD (16 yrs old, Ohio)!

Another way to create awareness is to purchase some of our **Awareness items** and wear them with Pride! Also, when you **shop amazon** be sure to bookmark and shop every time from our **FOD amazonsmile link** – we benefit from all of your purchases ALL year round by earning a certain percentage of your total purchase! Donations made to the FOD Group are tax-deductible and will help us as we plan for future Programs & Services.

**So please keep us in mind if you are able to donate anytime throughout 2020 and beyond!**

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**JULY** is Fatty Oxidation Disorders Awareness Month

**Expanded Newborn Screening Saves Lives!**

**Family Support Group ‘All in This Together’**

**Buying and selling on eBay to benefit the FOD Group!**

Since its program launch in 2003, eBay buyers and sellers have donated over $725 million through the eBay for Charity program to social causes around the world. We invite our FOD Family Support Group community to participate in the eBay for Charity program.

Start now with these easy steps:


- As your favorite charity on eBay, you can now directly donate to FOD Family Support Group at checkout when you purchase any item.

- You can shop for any items on eBay in which the proceeds are donated to our charity. Check out FOD Family Support Group's charity shop here: [https://www.charity.ebay.com/charity/FOD-Family-Support-Group/36781](https://www.charity.ebay.com/charity/FOD-Family-Support-Group/36781)

- You can sell your own items on eBay and donate a percentage of the sale price to benefit FOD Family Support Group

All of these efforts allow you to easily support our cause. Your donations are tax-deductible and as a charitable seller, eBay rewards your support by offering you a fee credit based on your donation percentage to FOD Family Support Group.

Your generosity makes you an example of why the FOD Family Support Group community is so special and shows the impact we can have together through individual acts of kindness.
We have had some deaths over this past year in our FOD Family… an adult LCHAD, a young man with TFP, a teen with MCAD, and a young LCHAD child

Please remember our Families in your thoughts and prayers throughout the year ~ All of our FOD children and adults will ALWAYS be with us in our hearts!

IN HONOR OF SABRINA GIANGRANDE
“My BFF”

If love were enough to keep me here
We would not be here today
In my case love was not enough
So I just couldn’t stay
I run around the heavens now
As free as a butterfly
And I really am sorry
That I had to make you cry
I promise I am here with you
My spirit will go on and on
So shed your tears
But not for long
Like me you must be strong
Honor me by having fun
The way I used to do
You had me for a little while
Now my time on earth is through
I will never really leave you
I am right here by your side
I love you as you loved me
Until the end of time
And when your journey here is through
I will lift you up with me
And we will be together again for all eternity

- All My Love The Girl Beeb

Sabrina, from the moment you were born, your smile lit up the room. You were loved more than words could ever express. We will miss you every second of the day. Rest in the sweetest peace our beautiful angel. Until we meet again.

Love,
Daddy, Mommy, Jillian, Papi, Girl Beeb, Boy Beeb & Linda, Aunt Kim, Luisa & Isabella

‘But in all the sadness, when you feel like your heart is empty, and lacking, you’ve got to remember that grief isn’t the absence of love…grief is the proof that LOVE is still there’

~ Tess Shaffer ~
Caregiver Action Network Hotline

**Caregiver Help Desk – It's Free!**

Contact our Care Support Team, staffed by caregiving experts, to help you find the right information you need to help you navigate your complex caregiving challenges.

Caregiving experts are available 8:00 AM – 7:00 PM ET.

CALL 855.227.3640

Advice for a Great IEP Meeting at School

**American Bar Association - Search for Pro Bono Attorneys**

Q: Do you have an easy way of estimating fat in something you cook from scratch?

A: [from various facebook comments]

There are heaps of free calorie tracker apps out there to try. MyFitnessPal even lets you scan the barcodes, create recipes etc. You can then go in to the nutrition for the day and see the percentages of the macro nutrients for that day 😊 and makes life a lot easier.

Yep, add up the fat from ingredient labels then divide by approximate amount of servings. For example, a batch of 12 muffins with skim milk, applesauce instead of oil and 2 eggs(10g fat) would be approximately 1gram per muffin (flour has some fat).... if that's too high or you think you child will eat two, substitute egg whites for an egg to lower the fat to .5 g per muffin.

Some common nutritional facts about fats, which have 9 calories per gram (if it's easier, use 10 calories per gram to estimate): Most oils are 14g of fat in 1 Tbsp; butter has 12 grams of fat in 1 Tbsp; eggs have 5g of fat each; cheese have about 9 g of fat per slice; 3 ounces of beef (85/15%) has 13g of fat; boneless and skinless chicken breast has 1g/ fat per ounce. Most fruits and juices are fat free. You can find milk, yogurt, marinades, jarred sauces, etc. that are fat free; check the labels. Some grocery stores have fat free cheese (American, cheddar, mozzarella, and others.)

We use the nutra checker app, it does it all for you and summarizes everything at the end of the day.

**Nutrient Values of Common Foods (in Canada)**

www.fodsupport.org
Please think about sharing ALL of the above for upcoming issues ~ for ALL Submissions please email to Deb

Pictures ~ please include their name, age, disorder, and state/country and that you give me permission to print in the Newsletter

Genetic Mistakes, Understanding and Living with Fatty Acid Oxidation Disorders, by Rosemary Forrest and Nicole Baugh, is published by Nova Science Publishers (ISBN#978-1-53612-244-2) and is on amazon

Rosemary is a CPT 2 grandma!

We are also looking for Families or Professionals to do their own Videos that tell their Stories or create FOD Awareness in other ways...such as sharing how they prepared for a school IEP, what is necessary to have ready before a hospitalization, how has their disorder changed as they have grown into adulthood etc. Then we can upload it to our FOD youtube channel! So email me if interested.

More Lifeline Support...

~ Facebook Groups for FOD Families ~

Main FOD Group for ALL FODs
LCHAD WARRIERS
Long and Very Long chain FOD food group
GA 2/MADD Families
Carnitine Deficiency (Primary and Secondary)
MCAD Deficiency
Raising Rare and Beautiful Children with CPT 2 Deficiency
Fatty Acid Oxidation Disorder (FAOD)
UMDF
CUD/Primary Carnitine Deficiency through Newborn Screening

LCHAD Poland
Parents of VLCADD Kids
Adults with FODs
Metabolic Support UK
MCADD Families UK
The Metabolic Foundation - UK
MCAD Norge
Ethan James Wyne MCADD Organization
Mitoaction

Genetic Mistakes, Understanding and Living with Fatty Acid Oxidation Disorders, by Rosemary Forrest and Nicole Baugh, is published by Nova Science Publishers (ISBN#978-1-53612-244-2) and is on amazon

Rosemary is a CPT 2 grandma!

NEEDED for JAN 2021 NEWSLETTER ~

KIDSKORNER PICTURES, FAMILY STORIES, SPECIAL ARTICLES, REACH FOR THE STARS, AND PROFESSIONAL ARTICLES ETC

www.fodsupport.org

‘All in This Together’
Thank you to all that have done their own ‘Facebook Birthday Fundraisers or In Memory of Donations’ to benefit the FOD Group ~ all the donations are greatly appreciated and will assist us in either our General costs, Networking and Educational Services & Programs, Grief Support, or other areas of the nonprofit that need funding!

Some of the Families that created facebook Birthday fundraisers or In Memory Of Donations since our last Newsletter included: Katy Boles, DeAnne Garlock, and the Family of Sabrina Giangrande. All of our current donations from the last 6 months are posted on our last page! If I missed anyone please let me know. Facebook sends the funds 30-60 after the end of the fundraiser so be sure to let me know when your Fundraiser ended and how much was raised. I will look for that in my automatic deposits ~ HOWEVER Facebook never sends me names so I don’t have any idea which Fundraiser it was from - so please let me know! And it doesn’t matter if nothing was raised monetarily...you raised AWARENESS and that is what’s important!

Also THANK YOU to the Committee members for the INFORM Network and the FOD Registry for all your work on FOD efforts~

Michelle Little, Dave Perritt and Brittany Leigh Pridal
Lindsay Johnston, Christy Perez and Brittany Leigh Pridal
FOD GROUP FINANCES

2019 FOD Group Tax Return is up on the site.

The bulk of Expenses are for monthly phone, website fees, supplies, MeetUps/Seminars, Insurances, and for our Grief Consultation office (rent, advertising, etc) to offer pro bono grief support to local Bereaved Parents & Families (and also via Skype/zoom to FOD Families around the world). We also donate FOD funds from undesignated donations to various FOD related entities (ie., for NBS issues, outreach) to support their efforts.

All Undesignated and Grief Consult donations are deposited into the General Fund or Gen Trust Fund, as are Awareness Item Sales, Cafepress.com, iGive, amazonsmile, etc and any donation that isn’t specifically designated. Online links are available for outside Research and Clinical clinics/individual researchers if you’d like to directly donate to their FOD efforts. No FOD money is used for salaries - we are an ALL Volunteer organization.

Additionally, we have a 1yr & 3yr certificate and long-term stocks/bonds earning interest and dividends for future FOD endeavors and programs.

Thank YOU [Donations since Jan 2020]


Some of the above donors have purchased Tshirts, Bracelets, Ribbons, CafePress, or used GoodSearch browsing, MissionFish/eBay selling, iGive or Amazonsmile.org shopping etc.

Thank you to all that have bought products from companies on the Internet that support the amazonsmile, iGive, GoodSearch and GoodShop, and Cafepress.com programs of donating a certain percentage to Groups like ours. All of those links are on our website.


We greatly appreciate donations to help with daily costs, website fees, insurances, supplies, Regional MeetUp/Seminar costs, phone calls around the world, rent for the Grief Consult office, and raising funds for future Programs & Services and long-term investments.

ALL donations go toward FOD efforts & programs.

US checks made payable to the ‘FOD Group’ mailed to: FOD Group PO Box 54 Okemos, MI 48805

Online Donations  Awareness Items

‘Hope lies in dreams, in imagination, and in the courage of those who dare to make dreams into reality’

~ Jonas Salk ~