



Newsletter

NATIONAL SUPPORT GROUP FOR FAMILIES WITH CRI DU CHAT SYNDROME

Volume 32

Issue 23

A Fond Look Back

by Jen Wong

I have been a part of the 5p- Society since 2002 when Emma was diagnosed at 4 months old. We were lucky that the geneticist gave us information about the 5p- Society and Laura Castillo quickly linked us up with Dawn Sadler (we were in Alaska at that time). Laura's information and support and Dawn's local support quickly gave me hope from the article I had found (which many of us have) that told me more than likely Emma would die by the age of 1. In 2005, we attended our first conference in St. Louis (my hometown). My biggest memory from that conference was it was the first time since having Emma I felt like I could breathe and relax. Everybody got Emma's cry, sounds, and behaviors and loved and accepted her whole heartedly. It's a time to recharge and reconnect with families that truly get every joy, sorrow, and frustration and validate it all. I was hooked by the love and support I was given that conference. I became interested in the business side of

the Society and became a Board member. At the 2012 conference in Denver, I became President.

Watching the growth of the 5P- Society over the last 10 years has been staggering. With the introduction of social media, our membership, outreach, and awareness sky rocketed. We have so many members willing to share their talents to continue to expand our mission; it's humbling to be a part of it all. The future of the Society looks bright and exciting. With many different emotions and long thought, I have decided to step down as President and allow someone with far more/better skills to step up and lead us onward and upward. I am confident with the support of the current Board Members; the new President will accomplish great things. The hardest part of this for me is, for the first time, I was unable to attend a conference. With Cedric's work schedule and our boy's activities/school

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2017 Awareness Week

Our 2017 Awareness Week was a huge success!! Many thanks to all who participated!

Caregiver's Handbook

We've had over 125 participants! And over 30 adult participants. We will begin putting it together after the conference. It's not too late to participate.

Contact Laura Castillo for more info.

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schedule, we just couldn't coordinate a plan to make it work. It's been a sad realization for me to not be able to attend and catch up with my 5P family as well as to pass on the gavel to my predecessor. I wished the Milwaukee host families all the best. Based on their hard work, I know this conference has been a success. Since they all stepped up to volunteer, I knew it would be a great one and was really looking forward to attending (and getting the mustard-horseradish salad dressing recipe from Hutch's restaurant). 😊

I would like to thank the Board members for all their hard work and support during my Presidency. A thank you is not nearly enough to say to Laura Castillo for all of her support, education, and patience she has given me (especially with this, my last newsletter contribu-

tion as President, which is REALLY past its deadline). I have always used the analogies that I was like the Queen of England that just waved and looked pretty (well, at least waved) or that I was the Wizard image in the Wizard of Oz and Laura was the man behind the curtain, doing all the work. I hope the incoming President is better at meeting this deadline than I have been. I would especially like to thank everyone for their friendship; it has truly gotten me through the lowest lows of Emma's CDCs journey and life in general. It has truly been an honor and privilege to lead the Society. I hope I leave this position having given the Society and its members at least 1/2 of what I have received from them.

LEARN SHARE CONNECT

YouTube Videos to watch

5p- Society "I Can" video
<https://www.youtube.com/watch?v=2AEvN0-6M6I>
2015 Virtual 5k for 5p- video Recap
<https://www.youtube.com/watch?v=EWX6NHj0nwY&feature=youtu.be>
Adam & Tyler Buckner on KASA morning news! 5/30/2014
<http://kasa.com/2014/05/29/cru-du-chat/>
Cri du Chat Awareness US
<https://www.youtube.com/watch?v=GbWDG3JXFL4>
 Video to increase awareness of Cri du Chat in the US and across the globe. By Larry McSeed
Cri du Chat Awareness Video—Australia Support Group
<https://www.youtube.com/watch?v=V6wk4bFVz2g> Australia Support Group awareness video for 2012 Awareness Week.
International Cri du Chat Syndrome Awareness— Meet Nellie
<https://www.youtube.com/watch?v=zw2joxiYjR4>
Emma's "Steps of Faith"
https://www.youtube.com/watch?v=giW_iP5ibr8&feature=youtu.be
Documentary by Maria Ripoli
<http://www.cromosomacinco.com/>
Meet James Chalmers
<https://www.facebook.com/james.chalmers.3994/videos/10207221038346912/>

Blogs to follow

- <http://livingwithcriduchat.blogspot.com/http://elastamom.com>
- [All Things Beautiful by Kathy McClelland](http://allthingsbeautifulbykathy.blogspot.com)
- <http://livingwithcriduchatmosaicism.blogspot.co.nz/>
- <http://mikeandbrittanierickson.blogspot.com>
- <http://thissideofordinary.blogspot.com>
- <http://beautifulunexpectedjourney.blogspot.com>
- <http://www.cdcslovehope.com/blogspot.com>
- <http://clairematilda.wordpress.com>
- <http://crazyincognito.blogspot.com>
- <http://myriverside.wordpress.com>
- <http://allaboutvayla.blogspot.com>
- <http://brennanandcalebsmom.blogspot.com>
- <http://praiseyouinthestorm.com>
- www.prayforellee.org
- <http://notquiteearthmother.wordpress.com>
- <http://tricia-themama.blogspot.com>
- www.angelarichey.blogspot.com/
- <http://lessonsfrommydaughter.me>
- <http://martianmommy.blogspot.com>
- <http://www.specialneedsdadchronicles.space>
- www.mydanceintherain.org

Books to read

A Book to my son Nathan: <http://www.mixbook.com/photo-books/interests/blank-canvas-8309369?vk=ymWDIdOAWC>
Raised by my Child by Sally D. Yantis-Grube, 2011—Mom to Heidi, 18-year-old with Cri du Chat Syndrome.
Her Name is Montel by Casey Evans, 2005—Dad to Montel, 20-year-old with Cri du Chat Syndrome.



Several parents who have been through the guardianship process discuss their thoughts about the appropriateness of getting guardianship for their disabled children.

Amy Severson's daughter Nellie is a few months away from turning 18. Nellie, who is afflicted by a rare chromosomal disorder called Cri du Chat (CDC), is developmentally disabled and has communication challenges. Like any well-informed parent of a child with special needs, Amy knew that the issue of guardianship

must be addressed a few months before your child turns 18. So, several months prior to Nellie's birthday, Amy began looking into guardianship options.

A researcher by nature, Amy spoke with several people in her New York community who she believed were knowledgeable about guardianship. Amy was surprised when an employee of a local ARC facility advised her to get a psych evaluation for Nellie to see if guardianship was even appropriate. The ARC staffer suggested that guardianship would "take away all of Nellie's rights" and that Nellie's needs could possibly be met with a simple health care proxy. This was unexpected advice and undermined Amy's confidence in moving forward with the guardianship. "From speaking with other parents of special needs kids, I just assumed that guardianship was the route we would take," said Amy. "I never considered that this wasn't the right thing to do." Conflicted, Amy reached out to her peers on the Five P Minus (5P-) facebook group for advice. The ensuing commentary revealed some anxiety about guardianship, especially among parents who have not yet completed the process. It also raised two important questions:

1. Is guardianship the right thing to do for adult children with Cri du Chat? And,
2. What's the best way to obtain guardianship if that's the route you decide to take?

I interviewed several parents who have been through the guardianship process (and those currently going through the process) to learn more.

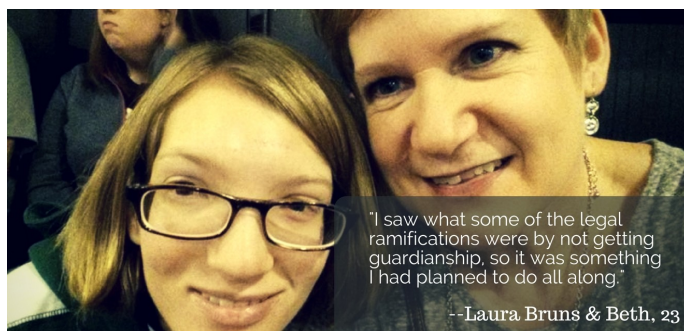
What is Guardianship?

Once someone turns 18, by law, the authority to make major life decisions transfers from the parents to the individual. At 18 you can, among other things, refuse or consent to medical treatment, enter into contracts and take on financial obligations. People with intellectual disabilities may not have the capacity to make these decisions on their own, particularly if they face communication challenges, have problem-solving deficits or are highly suggestible.

Guardianship is a mechanism by which a court makes a legal determination that a person, who is over the age of 18, is unable to make these decisions on their own, and authorizes a different person to have the legal authority to make these decisions on behalf of the disabled person. For parents of kids with CDC, guardianship is often simply a restoration of the same rights they had prior to their child turning 18.

Why do parents seek guardianship over their CDC children?

Safety was the primary reason the parents gave for seeking guardianship. For Ohio mom Laura Bruns, there was no hesitation about getting guardianship for her daughter Beth, who is now 23. Laura was involved in her local ARC and attended several guardianship workshops. She also had a family member with disabled children and saw what some of the



legal ramifications were by not getting guardianship. “My biggest concern was that Beth was vulnerable to being abused,” said Laura. “Guardianship was something that I had planned to do all along.” Beth, who is nonverbal, was starting to go out in the world without her mom. Laura was concerned that Beth could be accused of consenting to activity that she did not have the capacity to make.

California mom and 5P- Society Executive Director Laura Castillo initially put off the decision to obtain guardianship over her adult daughter Katie, who is now 30. But an incident with a door-to-door magazine salesperson influenced her decision to move forward with it. Shortly after Katie turned 18, Laura’s aunt, who is a paralegal, completed the paperwork to file for guardianship. But like many parents, lack of time and one more expense to bear delayed things. “Probably the reason I put it off for so long was because Katie could talk, so she could say ‘give mom permission’ wherever consent was needed,” said Laura. But fears of Katie getting swindled motivated Laura to follow through with guardianship. While Laura was away at a 5p- Society board meeting, Katie had let herself into the family home about the same time that Laura’s husband, Mike, pulled into the driveway. While Mike finished up a phone call in his car, a door-to-door magazine salesperson rang the doorbell. Katie answered the door and let the person into their home. Mike rushed in to see what was going on, and the salesperson said to him, “well, the lady of the home invited me in.” While no harm was done, the experience was enough to motivate Laura to complete the guardianship paperwork.

A more life-threatening situation propelled Nevada mom, Yolanda Strauss, to seek guardianship over her son Michael, who is now 25. Michael needed emergency surgery to correct severe scoliosis. His spine was creating pressure on his body that could have collapsed a lung or caused heart failure. When Yolanda and Michael went to get blood work prior to surgery, hospital administrators insisted Michael sign a consent form. Michael was unable to sign the form and the lab refused to do the bloodwork. Luckily Michael’s doctor intervened and was able to push the lab work and surgery through, but he insisted that Yolanda get guardianship for Michael to avoid this situation from happening in the future.

How did parents feel about getting guardianship over their children?

In the comments to Amy Severson’s facebook post, a few parents who had not yet been through the guardianship process expressed trepidation about taking away the rights of their children. But the parents I interviewed were all pleased with their decision to obtain guardianship. “I never felt guilty,” said Wisconsin mom Denise Ladwig. “Guardianship just gave me the same rights as I had before.” Denise’s daughter Kayla is 26

and is non-verbal. “I knew I had to be Kayla’s legal guardian because she can’t read or write, and can’t speak. It never crossed my mind that I was taking rights away.”

Some parents expressed frustration with the guardianship system generally. “To get the guardianship, Beth had to be declared ‘incompetent’ and it kind of startled me a bit,” said Laura Bruns. “But knew that I was doing it for her protection, so I didn’t feel that terribly guilty about it.”

Did parents hire a lawyer to get guardianship?

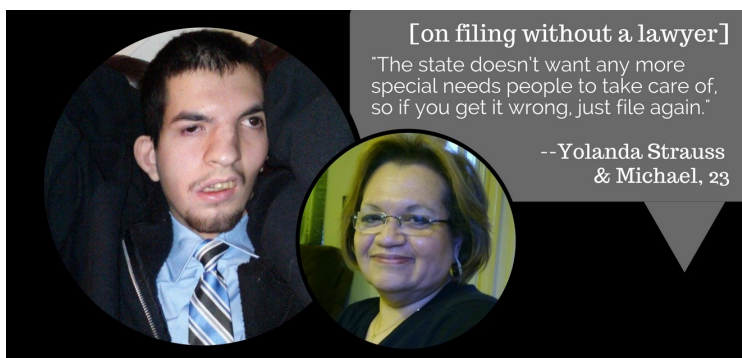
The process for obtaining guardianship is different in every state. Some states have very easy processes, others are more complex. The parents interviewed were evenly split in terms of whether they used an attorney to represent them in the guardianship proceeding. For those who hired a lawyer, peace of mind that the process would be done correctly was cited most frequently. “I wanted to make sure the guardianship was iron-clad,” says Ohio mom Eileen Sherman, who hired a local lawyer to get guardianship over her daughter Heather, who is now 36. “The lawyer made everything very smooth,” said Eileen. “He explained the whole process to the family, and advised about the things the judge would ask at the hearing.”

Laura Bruns also hired a lawyer and was satisfied with her decision. “It didn’t really come across my mind that I would do the guardianship on my own,” said Laura. “Even though I worked in a local courthouse, I didn’t know where to start.” According to Laura, the lawyer made the process relatively easy.

Denise Ladwig had a similar experience. “I never considered doing the guardianship on my own,” said Denise. “When it comes to legal stuff, I’m the kind of person who wants it done right.” But it’s been several years since Denise filed for guardianship and even she conceded that, with resources now available online, she would have at least researched filing for guardianship on her own.



The Saylor, Yolanda Strauss and Amy Severson were among the families interviewed who filed (or are filing) for guardianship without the assistance of an attorney. While many of the families interviewed would have liked the guidance of a lawyer, for most, saving a considerable amount on lawyers’ fees was the underlying reason to go it alone. However, most of the families who filed on their own had some form of assistance, either from a friend or advocate or from a helpful clerk at the courthouse.

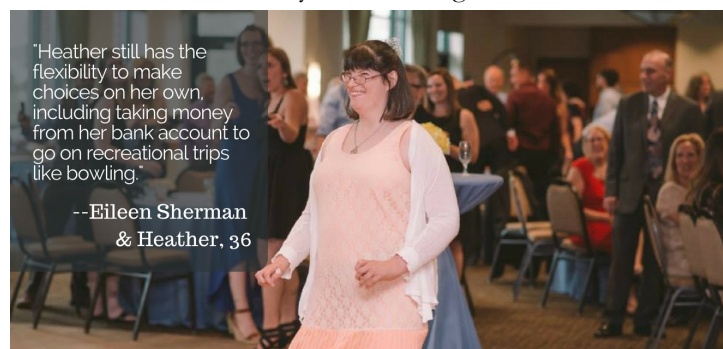


Though most of the families got through the guardianship proceeding on their own, in many cases these families experienced more anxiety about the process than the parents who hired a lawyer. This often stemmed from misinformation, or not having a complete understanding of the process, technical terms or all the options available to them. While some of the families were nervous about making a mistake, Yolanda Strauss had the most upbeat attitude about it. “Your kid is still your kid,” said Yolanda. “The state doesn’t want any more special needs people to take care of, so if you get it wrong, just file again.”

On a functional level, how does guardianship work?

Most of the parents found that once they got guardianship, nothing really changed and their children still very much participated in all decisions affecting their lives. Once the court approves your application, the parents reported taking the paperwork to doctors visits, school registration or meetings for government services, but many times don’t get asked for them. Even though the guardianship gives the parents final say on major decisions, all the parents interviewed have their children participate in those decisions. “We’re still giving the kids choices in life about most things,” says Denise Ladwig who, together with Kayla, is currently making a decision about a group home.

Eileen Sherman’s daughter Heather now lives in a group home, which checks in with Eileen for major decisions. Though Eileen has full guardianship over all Heather’s personal and financial affairs, Heather still has the flexibility to make choices on her own, including taking money from her bank account to go on recreational trips like bowling.



Same with Laura Bruns and Beth, who recently finished public school. “In figuring out what to do once school ended, we went to lots of places and she was involved in the entire process,” said Laura. “Beth went along to all those visits and had a say in what she liked best.” Laura and Beth found a work program they both liked, but Beth only wanted to work one day a week. So they both decided on a recreational day program for the other days. “She still has lots of choices to make in her life,” says Laura.

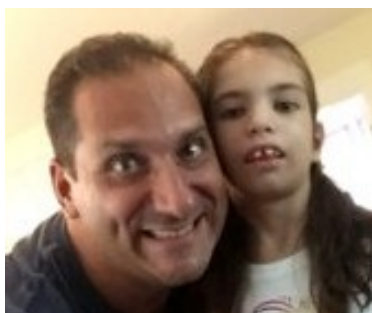
Is it a good idea to not get guardianship?

Without question, there is a movement to have disabled persons maintain as many rights and choices as they can. While it is possible for parents of adult children with disabilities to get by without guardianship, careful analyses must be made as to whether this is the best, and safest choice for your child. Such an assessment typically involves determining your child's ability to understand and retain relevant information, appreciate the nature and consequences of the most important life decisions they are making, and the ability to clearly express or communicate a decision.

All of the parents, including those who described their children as being on the higher-functioning end of the CDC spectrum, described their children as being emotionally immature, overly trusting and susceptible to suggestion. These are primary reasons to justify guardianship, particularly if your child's safety is a concern.

Without guardianship, other people like caseworkers, hospital administrators and financial institutions will also be assessing your child's capacity each time you deal with them. If your conclusion and theirs conflict, your child could be denied services because the other party believes your child does not have the capacity to consent. Parents who try to circumvent the guardianship process with a healthcare proxy granted by their child may find that very document called into question, since it's debatable whether a CDC child has the capacity to consent to the proxy in the first place, at least not without undue influence.

While foregoing guardianship may be appropriate for young adults with different disabilities, not getting guardianship is more likely the exception for CDC families, not the rule.



About the Author

Stephen Furnari is a Florida attorney who takes on pro bono guardianship cases for low income parents of special needs children. Furnari is developing the Guardianship Project, a low cost legal service that helps parents of special needs children apply for guardianship by combining group coaching and traditional, but unbundled, legal services. Stephen lives in Flagler Beach, Florida with his wife Kristi (who serves on the Board of the 5P- Society) and three daughters, including 8 year old Katie who is affected by the disorder. Connect with Stephen on Twitter @stephenfurnari

5p- Gear Items

There are several places that you can get your 5p- Gear. Many items can be found at www.cafepress.com/5pshop

There are also several items at the 5p- Society Square Market store. You can shop at <https://squareup.com/store/5p-society>

Items available:

- ⇒ Hats—\$20.00 each
- ⇒ Waterbottles—\$10.00
- ⇒ Decals—\$10.00
- ⇒ Magnets—\$8.00
- ⇒ Coffee Tumblers—\$10.00
- ⇒ Wristbands—\$5.00
- ⇒ Keychains—\$5.00
- ⇒ Calendars—\$20.00



This is a Public Service Announcement

We received some really GREAT NEWS recently! If you live in Dallas/Fort Worth or Houston the PSA that the very talented Cheryl Allison (who is the cousin of a parent to Cole) from Wow Films, LLC has created for the 5p- Society will be shown on Fox 4 and MY27 (North Texas) and Fox 26 and My Network (Houston). Cheryl is also looking at pushing out the PSA elsewhere with her connections. AND Cheryl was encouraged to submit the PSA to The Hermes Creative Awards, an international competition for creative professionals involved in the concept, producing, directing, writing and design of traditional materials and programs, and emerging technologies. Many production companies submit their creative work. She was notified yesterday that the PSA won a GOLD AWARD! They had 6,000 entries and only 22% won gold awards. CONGRATULATIONS CHERYL!!! We are so proud of you and so very thankful that you have shared your talents and spreading awareness!!! #5pminus #cri duchatawareness #wowfilmsllc #teamcole View the PSA by visiting the 5p- Society FaceBook page.

Introducing our New President: Nick Wallace



I have been asked to introduce myself and my family so that you can get to know a little bit about your new board president and his family.

I know several of you already know me from losing a bet and having to perform as Gladys Knight at the New York conference or from co-hosting the Ohio conference in 2011. For those that don't know me, my name is Nick Wallace. I have served on the Board of Directors for 12 years now, and for the past 5 years I have served as Vice President. My family and I live in the small town of Bellefontaine, Ohio.

My wife, Angie and I were high school sweethearts. So, she knew what she was getting into when she married me. That is why most people wonder what she was thinking when she said yes to my proposal. During our dating years, we would have never thought that we would be involved with the 5p- Society. Actually we didn't even know what the 5p- Society or Cri du Chat Syndrome was until the birth of our daughter, Allie, who has Cri du Chat Syndrome. Over time, we have taken it upon ourselves to advocate for Allie by educating local students, teachers, medical professionals and community members about Cri du Chat Syndrome. As you have all come to understand, being a parent of a child with special needs is not always sunshine and roses, but for us the positives do outweigh the negatives.

Our journey with Cri du Chat Syndrome started 13 years ago when Allie was born. Allie was diagnosed with Cri du Chat Syndrome at around 2 months of age. I would like to say that the

beginning of our journey was a pleasant one, but it was more like walking barefoot down a dark hallway with Lego bricks scattered down the entire thing. When we were given the news by a geneticist, we were given information about Cri du Chat from the 1970's. We soon realized that the information was outdated. We were fortunate to live in the age of the internet and were able to find resources like Tiffany and Matt Townsend (who lived only a couple hours away) and our own 5p- Society. We attended our first conference in 2004 when Allie was only 6 months old. The information we were able to obtain from the families we met and the conference presentations gave us hope for the future. This experience is one of the reasons I am so passionate about our International Cri du Chat Syndrome Awareness Week initiative. We need to continue to raise awareness and get current information regarding the syndrome into the hands of doctors and caregivers across the world. Receiving the diagnosis is hard enough, but with the current information, it is like giving the parents a pair of shoes to traverse the dark, Lego strewn hallway.

Angie and I have two other kids, Nate and Laney. Nate is what is known as a conference baby. We decided to have Nate (12 years old) after attending our first conference. We heard so many families saying that it is a good thing to have a child close in age to your child who has Cri du Chat Syndrome. The siblings will help teach each other and will aid them in their development. For our family, this has proved to be true. Through their sibling rivalry, Nate pushed Allie's development more than we ever could have done alone. In return, Allie has taught him compassion and patience. Nate is one of Allie's biggest advocates and the bond they share is beyond words.

Laney (4 years old) has also learned a lot from Allie. Even at a young age, Laney is concerned for the well-being of her sister (unless she is trying to manipulate Allie to get something she wants from a place that is out of her reach). Recently Allie had to get bloodwork and Laney had nightmares about it because she was so concerned for Allie. She also will stick up for her sister if she feels someone is wronging her in some way. No one gets to wrong Allie (except Laney), so don't even think about it! I have a feeling Laney will grow up to be a strong advocate for Allie, just as Nate is.

So, that is our crazy family. I look forward to working with Laura and the rest of the board, as well as all of you. The society has made so many strides over the years and I am excited to see where we will go in the future.



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Meet C5

The Mascot of the International

Cri du Chat Awareness Week

May 5-12, 2018

WE'RE ON THE WEB
WWW.FIVEPMINUS.ORG

TWEET WITH US
[@5PMINUS](https://twitter.com/5PMINUS)

FIND US ON FACEBOOK AT [HTTP://WWW.FACEBOOK.COM/CRIDUCHATSOCIETY](http://WWW.FACEBOOK.COM/CRIDUCHATSOCIETY)

YAHOO GROUP PAGE: 5PMINUS
[HTTP://HEALTH.GROUPS.YAHOO.COM/](http://HEALTH.GROUPS.YAHOO.COM/GROUP/5PMINUS/JOIN/)
[GROUP/5PMINUS/JOIN/HTTP://HEALTH.GROUPS.YAHOO.COM/](http://HEALTH.GROUPS.YAHOO.COM/GROUP/5PMINUS/JOIN/)
[GROUP/5PMINUS/JOIN/](http://HEALTH.GROUPS.YAHOO.COM/GROUP/5PMINUS/JOIN/)



HAVE YOU SEEN IT?

Thanks to Adam Greenberg and his team the "I Can" video production is complete. You can see it at <https://www.youtube.com/watch?v=2AEvN0-6M6I>

Calling ALL Ages.....2018 Faces of Grace

Cri du Chat Syndrome Calendar

It's that time of year to start looking forward to the 2018 calendar! The calendar features twelve beautiful Individuals with Cri du Chat Syndrome. To qualify for your child/adult to be one of twelve selected, they must 1) be members of the 5p- Society, 2) have not participated in a previous calendar spread. ALL ages are welcome! If interested please contact Laura at director@fivepminus.org.

