



THE ELDRIDGE GAZETTE

Embracing a future of possibilities

FAMILY ADVOCATES UNITED / PHA



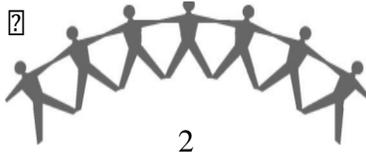
AUGUST 2019 ISSUE

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www.parenthospitalassociation.org

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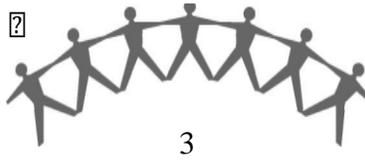


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Save the Date

General Membership Meetings:
Hanna Boys Center, 17000 Arnold Dr., Sonoma, CA

- September 14, 2019, 10:00 AM
- March 14, 2020, **10:30 AM (note new time)**, Annual Legislative Meeting,
- September 12, 2020, 10:30 AM **(note new time)**, Annual Business Meeting
- *Note: Regional Center Chapter Membership Meetings to be announced*



KATHLEEN MILLER
Co-President's Message

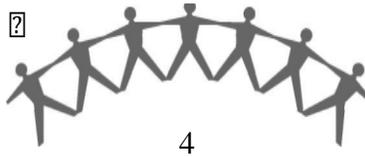
A TIME OF TRANSITION

Nothing is certain but change itself. I know there was a time not too long ago when we all felt safe in the knowledge that our loved ones were at Sonoma Developmental Center. It was one center that had the full support of the surrounding community and our local legislators. It felt secure. Now the developmental system of care is gone and many others are secure in the knowledge we have gone to an entirely community based system of care. They feel community care is the best way to meet the needs of the disabled and feel their job in seeing an end to developmental centers is done. In their view all is now well in the system of care.

The truth is we have no idea what will happen to the system of care for the disabled in the days to come. I know that many of us are delighted with the care our loved ones are now receiving in community homes. I am one who is happy with the care my son receives. Most of those moving from SDC have received quality homes in the community. Some have the added benefit of the new Sonoma Health Clinic to provide ongoing medical support. We have the advocacy of our legislators and local community to thank. Our own advocacy has also played a key role. Let us take a moment to give thanks and to pat ourselves on the back for some hard won benefits for those we love.

Now that we have taken that moment it is time to move forward. Change is once again upon us. The political picture is cloudy, those families with disabled loved ones not coming out of SDC continue to struggle and seldom receive the level of benefits the SDC movers enjoy. Many keep their disabled family members home, some by choice, others because they are offered no safe alternative. Despite this fact, they see no reason to join our organization to get the support of a family based advocacy organization. They continue to struggle on their own. Amid the changes there are changes within PHA. We will have new leadership and a new name and new by-laws to reflect some of the changes needed in order to continue our role of advocacy for the disabled community.

Our mission going forward however, is clear. How do we ensure the homes and other services retain the quality that has been put in place for those moving from SDC? How do we reach out to families who thus far see no reason to join us in our



advocacy? How do we ensure that others enjoy the same level of care our loved ones enjoy? How do we expand access to dental care and spiritual care for the disabled? These are just a few of the issues we must be ready to face and move into if we are to continue to succeed in our role as advocates.

We are unique in our role of independent family advocates. We have enjoyed a degree of success. Some of you may feel our work is done and are ready to pass on the work of advocacy to others. But make no mistake—we are never really done. The moment we relax and shift our focus is the very moment things may begin to once again change. There will always be those rare providers who are in the care of the disabled as an act of love—they will never change. But as others move on the care may begin slip. Budgets may be cut, services may dwindle. Our eyes and ears and voices remain critical if we are going to ensure quality care for the disabled. We must speak for them when they are not able to speak for themselves.

Please give our new president the same love and support you have given me these past many years. Our loved ones deserve nothing less.

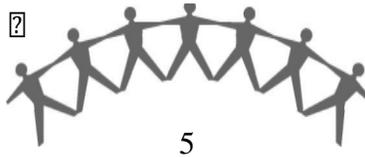
BRIEN FARRELL
President-Elect's Message

Family Advocates United is our new name. While the goal of compassionate, high quality care remains the same, the new name reflects that we are no longer linked to the hallowed site that two moms fought to acquire for our families in the 1880s.

Now that we are scattered throughout northern and central California following the closure of Sonoma Developmental Center, it is more important than ever that we consistently and clearly deliver our messages to our homes, day programs, regional centers, the Department of Developmental Services (DDS), the Governor, and our local legislators throughout the region.

I have learned much from Kathleen about administrative and legislative and family advocacy. She has been a tireless warrior for all of our families. I will continue to reach out to her. Under Kathleen's leadership, we succeeded in obtaining a world class health hub in Santa Rosa, excellent, beautiful, renovated homes, many good day programs, and appropriate consultant services. Our organization has influence in Sacramento because of Kathleen's expertise, relentlessness and love of her son, Danny. Thank you, Kathleen.

Kathleen has described our challenges. In most ways, closure has not changed our goals. But, more than ever, we need to carefully identify and urge ongoing support for all of those things



that are working. Since most of our family members are receiving very good services, we need to convey specifically to DDS, regional centers and the legislature what is working, so that care will not erode and budgets for existing services will not be cut.

Meanwhile, we must effectively describe problems and seek improvements in *Support Living Services (SLS)* homes, expand and enhance the capacity of the safety net for those with behavior diagnoses, promote integrated mental, dental and mental health care for all, not just those in Sonoma County, and advocate for sedation and anesthesia dental care, support suitable and sustainable day programs, including work opportunities for individuals interested in having paid work opportunities, and urge that state government authorize reimbursement for at least a living wage for direct care providers who are the backbone of the community system.

And we will never lose sight of the issues that arise for specific families and their loved ones. We will continue to fight for families denied necessary services.

We have a strong board. Please introduce yourself to members of the board of Family Advocates United who you do not know. They all have a deep commitment, and special expertise. Our officers are: Karen Moen, Vice-President, Bev Austin, Secretary, and Carol Price, Treasurer. They have vast experience.

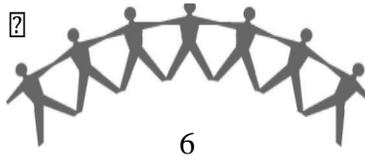
There will be opportunities to serve on subcommittees. We need the energy and talent of all members. We will make a difference together.

We are recruiting families, especially those whose family member never lived at SDC. We are now all part of a single system. We know that the system is complex and that mistakes and misunderstandings occur. The system has gaps. Not all families are confident advocating for their loved one. Family advocacy is vital.

To increase our impacts, we need to understand more fully the gaps in service, the occasional loss of good programs, and the systemic issues faced by those who have never lived at a developmental center. Together, we can refine our goals and expand our influence. We are now working on behalf of tens of thousands, not a few hundred, family members.

Cindy Cahill, a new board member, is part of a non-SDC family (her son did receive care for ten months at North Star on the SDC campus). She has helped us and will continue to help us understand the issues of non-SDC families, so that we can advocate forcefully for them, as well as SDC movers.

We are also inviting former SDC staff to join with us and have created a special membership category for them. They created a culture of caring and dedication. They felt joy being with our loved ones. They often showed us how to express our love and to be present with our family members. We welcome their knowledge and compassion.



If you meet families or know former staff, who might be interested in joining Family Advocates United, invite them to come to a meeting. They can find how to join at our web page- <http://parenthospitalassociation.org> . Please feel free to call, text or email me about any suggestions, questions or concerns.

Brien Farrell, President-Elect
707.494.7090
brienfarrell@yahoo.com

PHA
General Meeting Minutes
June 8, 2019

The meeting was called to order at 10:05 by Kathleen Miller. Guests were Dr. Stephen Okawa, Karen Toto, and Dr. Anne French.

The minutes from the previous meeting were approved.

Kathleen has several announcements. There will be a name change for PHA now that we are no longer associated with the developmental center. The new name will be PHA/Family Advocates United. The next general meeting will be in September. It was suggested that a representative from the North Bay Regional Center be invited to come. New by-laws will be presented in September. There will probably be less general meetings in the future and there will be meetings by regional center affiliation.

The documentary about SDC is complete. The film looks at the closure of SDC. There are interviews with some family members of those who moved from SDC. There are also interviews with former SDC staff and some others. There will be a showing of the film at the Sebastiani Theater in Sonoma on August 4 at 1 pm. There may be a panel following the showing for comments and questions.

On June 15 at Hanna Boys Center at 9 am there will be a meeting to give updates above the future of the SDC land. This past week a group of representatives from the coalition met at the cemetery on SDC to consider steps to take to preserve the cemetery. They hope to have a small parking lot near the cemetery along with information posted about the cemetery.

A handout has been created with information about PHA and how to join.

Kathleen has people at the meeting introduce themselves.

A concern that some SDC movers almost lost their SSI benefits and/or Medicare/Medical benefits because of some problems with financial issues. It was suggested that family members look carefully at what New Leaf (the fiduciary for many of those who moved from SDC) arranges and what you are asked to sign. After people move from SDC (or other developmental center), there can be a lag in getting everything in place and often the regional center funds the person for a period of time before things are settled. The regional center is later reimbursed.



While that is happening the SDC mover can have the amount in their funds go over the limit to be able to get SSI and Medical and that can create a problem.

Kathleen introduced the guests and had Karen Total introduce herself. Karen Toto is the Executive Director of Aleana Community Living. She has been in the field for 35 years. She worked on setting up the Schreiber Center which provides mental health services for adults with intellectual and developmental disabilities. She would like to see such centers throughout California.

Dr. Steve Okawa served as a dentist at Agnews, SDC, and now at Napa. He was providing dental care at SDC two days a week during the warm shut-down of SDC. He took the last patient last week and is now at Napa.

Dr. Anne French was at SDC and is now at Santa Rosa Community Health on Dutton in Santa Rosa. The clinic has been open since 2018 and is quite busy. They just provided dental care for a patient needing oral sedation. The clinic has patients who were at SDC and also patients who were never at SDC.

Kathleen said we need to learn about programs that are working so they can be replicated elsewhere in the state. She said that the death rate for those who have transitioned from SDC has slowed.

Karen Toto said that Dr. Schreiber, a psychiatrist, and her husband were seeing patients who had special needs. Both died within six months of each other. Sandi Soliday worked to get health care services set up which would provide mental health care. We know that people with developmental disabilities can also have mental health needs. The Schreiber Center was modeled after the Puente Clinic which offers mental health services for developmentally disabled in San Mateo County. The Schreiber Center only offers services to people meeting special criteria. They have had good attendance rates (90%) with few no-shows for appointments.

Dr. French said there is a lack of training for medical professionals to enter the field of serving people like those who moved from SDC. There is a nationwide shortage of psychiatrists. Schools training doctors, dentists, and other medical people need to provide some training about the developmentally disabled. Dr. French said the Santa Rosa clinic has their first person coming for two weeks to get some training on how to serve the developmentally disabled.

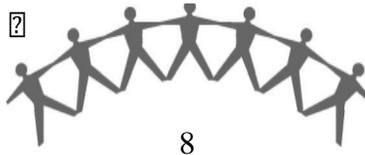
Kathleen said there are people with behavioral issues who are non-verbal or have very little communication skills who need services. There is a concern about how those patients are able to get help at a clinic.

Karen Toto said that there are many criteria you look at when a person has a psychotic episode or similar event. Someone who has autism might have behaviors that are handicapping and can become a client at Schreiber.

MHSA (Mental Health Services Act) which provides state money to counties for mental health services helped to fund the Schreiber Center.

Dr. French said that it is very important to get to know the patients. It is hard to know what some of the patients understand. Some are not very verbal, but understand more.

Dr. Okawa said that one his dental hygienists was asked to spend a couple of days in Sacramento to help with the legislative analyst's report on dental services for the developmentally disabled. The people in Sacramento told the hygienist that they knew nothing about dental care for the disabled. There are 21 regional centers in the state and they are pretty



independently run, so it is hard to coordinate a dental program statewide. Not all regional centers have a dental coordinator and some basically have no dental program.

Kathleen said that anesthesia for dental work needs to be available county by county. Maybe each regional center needs to have a dental consultant. Maybe dental work requiring anesthesia could be done in a surgery center instead of a hospital. The PDI (Pediatric Dental Institute) Surgery Center in Windsor provides dental care for children. They provide full dental services and have children from all over the state coming for their services. We need to have a similar clinic for adults. Kentucky has a clinic that has worked to get people to need less sedation when getting dental care. We need to start sharing strategies of how to set up services and fund them.

There is a wage rate study in progress in the state. Some people want to get rid of specialized rates.

Naomi Fuchs is talking about having funding streams for medical clinics that do not go through the regional center.

The clinic in Santa Rosa on Dutton is a federally funded health clinic. That clinic got seed money to create the special clinic. The clinic is integrated medical, dental, psychological, and other services all at the same place. They have a nurse case manager. They are also committed to longer appointment times since DD (developmentally disabled) often take longer to serve. They have funding now, but there is a concern about funding in the future. Santa Rosa also has a behavior psychologist who helps coordinate between the clinic and the home.

Santa Rosa is having problems with mental health and funding services for those people. Nationwide there is a shortage of beds for people who have crisis needs.

Kathleen turned the meeting over to questions and comments from the audience.

We want to be sure that staff is maintained in the homes. There are concerns that community behavior homes can keep staff. There have also been concerns about supported living. SLS (supported living) has been overused by North Bay Regional Center. There are some in that system who are not really ready to be in that type of system. There can be a danger to staff and to clients.

Mike said his son is not in dental Cal, but Kaiser. He asked if PDI took private insurance. Dr. French said that it does take private dental insurance. The Santa Rosa clinic has not connected with Kaiser yet. Dr. French said she would like people from Kaiser to come to the Santa Rosa clinic to learn some skills about how to care for the DD (developmentally disabled).

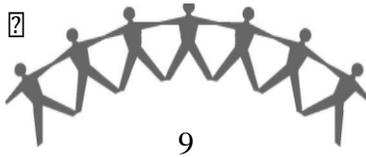
Kathleen said there are risks with specialists who think they know how to treat DD, but do not really know.

Some dental work is done in the homes. Alan Wong at UOP is helping replicate his services throughout the state. He has a training module to train people to work with DD.

What happens if there is a dental emergency with one of the behavioral people? Santa Rosa has emergency appointments. UCSF and UOP have wait lists, but can fit in some emergencies sometimes.

Kathleen asked the guests what one thing PHA could do.

Karen Toto it is important to get people to talk to each other and that the regional center has to be at the table. Stephen Okawa said that headquarters needs to understand the problem. There should be a few state clinics to handle those who need more complex dental care. Dr.



French said we need champion parents, legislators, and health care workers. We need to collaborate with national organizations. We need to build a desire in people to work with this population (DD). They can see the joy of working with these people.

The paperwork we have to sign is cumbersome. A health passport can help tell the story of who your loved one is. Dr. French sent it to PHA and it will be on the website. Make sure the home where your loved one is living has an up-to-date grab and go packet. Legislators do not know all the information about medical funding. They count on people like those in PHA and others to help them get the information.

The next North Bay Regional Center meeting will be on June 10 in Santa Rosa.

The meeting was adjourned at noon.

Memberships:

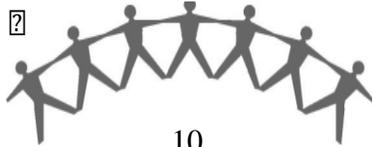
Time to renew your 2019 PHA membership now

Just a reminder that it is time to renew your 2019 PHA membership, if you have not already done so. The membership form is on the following pages or at <http://parenthospitalassociation.org/wp-content/uploads/2018/11/2019-PHA-Membership-Form.pdf>

All membership forms and fees should be mailed to Ms. Beverly Austin, PHA, 2683 17th Avenue, San Francisco, CA 94116. Your \$25 individual or \$30 family membership fee helps support the work of PHA.

Thank you!

Karen Moen, PHA



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PHA MEMBERSHIP FORM

For membership January 1–December 31, 2019

Make checks payable to : PHA

MAIL DUES AND DONATIONS TO:

**Beverly Austin
PHA (Parent Hospital Association)
2683-17th Avenue
San Francisco, CA 94116**

Check which type of membership below.

MEMBERSHIP DUES: \$25.00 Individual

\$30.00 Family (individuals with same address)

If donation included, please indicate the donation amount here: \$ _____

PROVIDE THE FOLLOWING INFORMATION FOR PHA (Please Print Clearly)

Name: _____

Address: _____ (Street)
_____ (City/State/Zip)

Check here if this is a new address since 2017

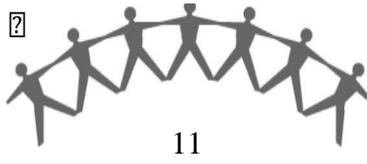
Telephone: _____ Email: _____

Would you consider being on the PHA Board: Yes No

Would you consider being on a PHA Committee: Yes No

Please check all that apply: Family Member Conservator

Former SDC Staff Other: _____



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