Parents Coordinating Council Meeting

When: Saturday — March 19, 2011
Start Time — 9:30 a.m.

Where: Lanterman Developmental Center
3530 Pomona Boulevard
George DeBell Auditorium

The March 19, 2011 meeting will feature Lanterman family members who traveled to the San Jose area to visit homes and community services for former Agnews residents, meeting with residents, families, and staff. Their report on this trip will highlight some of the Agnews closure options which are now part of the Lanterman closure, and give insight into the lives of the former Agnews residents.

Also, Marty Omoto Executive Director of the California Disability Community Action Network www.cdcan.us will give us accurate and unbiased information on events in Sacramento that affect our family members and others with a developmental disability. His tremendous knowledge of the DD system and his belief in the value of family advocacy will make this an extremely informative and important presentation.

The business portion of the meeting will call for Bylaws Approval – The proposed changes to the bylaws, mailed to all PCC members, will be discussed. Submitted comments to our bylaws changes will also be reviewed.

Co-President’s Message – Terry DeBell – Dorothy Juarez Fulco

Over the past many decades, families have been very active in helping to make Lanterman a good home for their loved ones. However, our work does not end now that the closure has been approved. We have been assured by the Department of Developmental Services that no one will be moved until all services and supports are in place. LANTERMAN FAMILIES need to be part of that process to make sure that happens. YOU need to learn as much as you can about community services and how this system works.

There are many opportunities and resources available for families to get involved in the future of their relative. Regional Centers are having group and individual meetings to introduce Lanterman families to community services, and we urge everyone to attend these meetings when you are asked to do so. The Closure Plan includes three Advisory Groups (Resident Transition, Quality Management, and Staff Support)
and families are serving on all of these committees. Some Regional Centers have included families on the review of proposals for the development of community services for Lanterman residents. The PCC has written information available on community services, IPPs, and legal options, and has offered informational meetings with guest speakers from DDS, Regional Centers, and community providers. Our next meeting will feature Lanterman families who traveled to the San Jose area to visit homes and programs developed for Agnews residents, who will share their experience with us all. (See the Contact article on this trip.) This meeting will also feature Marty Omoto, Executive Director of the California Disability Community Action Network (CD-CAN), who will be sure to give us valuable information and an education in the power of advocacy.

Please continue your involvement in the life of your family member by taking every opportunity you can to learn more about placement options and services for your relative, whether they are currently available or to be developed in the future. Attending PCC meetings will provide you with much of this information.

Julia Mullen, Deputy Director of Community Services and Supports Division

Community Placement Plan: Development of Services and Supports for People Transitioning from a Developmental Center

This month’s column focuses on an important program that was used successfully during the Agnews closure for the successful transition of individuals to residential settings in the community. The program is called the Community Placement Plan (CPP) and it provides the foundation upon which the Department and the Regional Centers develop resources for the transition of Lanterman residents to future homes.

The goal of the Department for the CPP program is to enhance the capacity of the community service delivery system to meet the needs of residents moving from a Developmental Center (DC) into the community, when appropriate, and provide the resources necessary to avert individuals from admission to a Developmental Center. The CPP is designed to support two of the Department's Strategic Plan goals:

**Goal One:** Expand the availability, accessibility and types of services and supports to meet current and future needs of individuals and their families.

**Goal Two:** Develop systems to ensure that quality services and supports are provided.

The Department works in concert with each of the 21 regional centers as CPP plans are developed. Each RC’s CPP must reflect the needs of its community, be individualized, and reflect a partnership among the RC, the individual and his or her family, the DC, and the Regional Resource Development Project (RRDP).

Person-centered planning, which includes comprehensive assessments, is fundamental to identifying and developing an individual's needed community resources. Development of the person-centered Individual Program Plan (IPP) should include as many people involved in the individual's life as possible, including family members and developmental center staff knowledgeable about the individual's service and support needs.

Regional centers have developed a variety of community resources under the CPP program. The services and supports needed by each individual are identified through the planning team’s development of the IPP, and typically include resources such as living options, day services, health care services and transportation, among others.

Each of the Regional Centers involved with Lanterman are working with dedicated staff in the assessment of individuals in order to identify specific resources needed or available in the community. The CPP process is exciting and rewarding as new possibilities give way to realities.
Cheryl Bright, Executive Director, Lanterman Developmental Center

Over the past year many of you have assisted the Lanterman Executive Team in recognizing the importance of strengthening our partnership and communication with the Parent’s Coordinating Council (PCC). As part of the LDC Executive Team’s commitment to keep families informed, there have been a number of efforts attached to increasing our communications including:

- Executive Team participation and attendance at Parent’s Coordinating Council Meetings and Residence Parent Group Meetings.
- Ensuring feedback was received from the PCC in developing the strategic plan for consolidation.
- Soliciting participation of family members in Advisory Workgroups, including the Staff Support Advisory Workgroup and the Resident Transition Advisory Group.
- Improved communications between Social Workers and family members in assuring documented family contact information is accurate, and the identification of who family members may contact should issues or concerns arise.
- Including Parent Coordinating Council representatives when tours with legislative members occur.

In addition to these efforts, enhancements to the Lanterman Regional Project (LRP) have been made to support resident transitions. As many of you are aware, Danette (Danny) McCarns was assigned as Interim Director of the Lanterman Regional Project on October 2010. Since Danny’s appointment, the Regional Project has made strides in building better relationships with family members, regional centers, clients and program staff. Additionally two Community Program Specialists from the Regional Project of the Bay Area have been assigned to support the LRP’s efforts.

Our commitment continues to focus on ensuring the services and quality of life for LDC residents entrusted to our care, will continue to be provided. As the Executive Director, I appreciate and welcome any ideas or feedback that you may have to continue our communications.

February 5, 2011 Meeting

The PCC meeting of Saturday, February 5, was highlighted by a panel composed of many individuals representing organizations that will have a strong influence on the futures of the residents, families, and staff of Lanterman Developmental Center. Assemblymember Norma Torres, who represents Lanterman residents in the state Legislature was joined on the panel by Terri Delgadillo, Director of the Department of Developmental Services. Regional Centers who have clients at Lanterman were represented by their Executive Directors and/or their staff. Also in attendance were representatives from the Southern California Integrated Health and Living Project and from Senator Gloria Negrete McLeod’s office. PCC Board members Terry DeBell and Art Lopez served as moderators.

Assemblymember Torres reiterated her commitment to the residents of Lanterman, and her intent to follow the closure closely. She assisted the panel discussion by requesting clarification on several points, including the IPP process, transition, and the budget.

Terri Delgadillo shared sections of the DDS Budget Highlights, and the Update on the Closure of Lanterman as submitted to the Legislature January 11, 2011–02–12. Although DDS is facing severe budget cuts, there is dedicated Community Placement Plan money for the closure of LDC for this budget year and next year. There will be challenges to provide services with impending budget cuts. DDS states commitment to ensuring that everyone has services they need - LDC residents will not be placed until all services are in place.

Regional Center (RC) Directors and staff answered questions on the transfer of LDC residents to other Developmental Centers, which is specifically mentioned in the Closure Plan. The overall response was that a transfer would be possible if the ID Team agrees to that placement option. There was a discussion on the development of the special medical model homes called for in the Closure Plan, and how individuals can move outside of their RC catchment area to be nearer to families and friends. There was a
lot of concern expressed with the quality of training for community staff, and the safety of community buildings. The budget crisis was discussed, along with the ability of RCs to provide services with limited funds. Regional Centers expressed a commitment to providing all services and supports for residents, and working with families in the placement process. Additional RC staff was available at end of meeting to work with families on individual problems, and were able to address several issues directly.

We are very grateful to all our panel members who participated in this informational meeting, and to all the meeting attendees who came to learn more about the process that will affect the future of their family member and how they can be involved.

**Lanterman Families — Impressions of January 20, 2011 Tour of San Jose Homes**

Below are several opinions expressed by families relating to the homes developed for the Agnews movers. Come to the March 19 meeting to hear families share their impressions and learn more about what type of homes and services can be developed for the Lanterman residents. If there is enough interest, PCC will arrange another trip to San Jose with other service providers.

**Jackie and Lee Bayer**

Our reason for traveling to San Jose was to learn about the homes provided the clients of Agnews DC under the 962 legislation. We feel that we should learn as much as possible before it is time to make a decision for our son.

We found the homes were designed to fit the needs of the developmentally disabled. They were modern, clean and beautifully decorated. We met several previous Agnews employees who now worked in these Elwyn Homes. I especially liked that the homes were to be permanent homes for the residents.

We visited a day center where the disabled worked at a paying job. It was a large quiet building. The disabled employees were friendly and it was apparent they were happy at their work stations and jobs. We truly enjoyed visiting with the client/employees. The manager of the center had worked many years of experience with the develop disabled.

The visit brought out more questions:

- The Elwyn Homes have a very small number of former Agnews DC clients. How many Lanterman DC clients will be able to take advantage of the “962” homes?
- The people we met didn’t need the higher lever of care required by the Lanterman men and women. Will these homes be able to meet the higher lever of care needed for our loved ones? Will my son have the advantage of the new “962” homes?
- Will California’s budget pay for not only establishing these homes with all the needed services but maintaining them for many years?
- Crisis intervention; are these homes able to handle a behavioral crisis without calling 911.

What will happen to our son? I know that is the heartfelt question that we all are asking. Then we all should look carefully into each facility that will meet the unique needs of our children; then share what we find with each other. Perhaps then we will have a good outcome and future for our loved ones.

**Terry DeBell**

I have visited homes for the former Agnews residents before, and greatly enjoyed being able to visit again with Lanterman families. The information provided by staff, families, and the residents of the Elwyn homes themselves is very helpful in being able to see how individuals with needs similar to those of Lanterman residents can be cared for in a community setting.
The key seems to be quality staff and a quality program. At Lanterman, we are used to RNs, Psych Techs and Psych Tech Assistants (PTAs). In the community settings that we visited, there were RNs, LVNs, some Psych Techs and Certified Nursing Assistants (CNA), which is equivalent to the PTA. Some of the staff members we met were former Agnews staff, who spoke very positively about the ability to work in this new setting with people they had worked with at Agnews. All staff members stressed that the needs of the individual comes first – and that program decisions are made based on those needs. This may require increased staff at some times, a request that is honored by the Elwyn management. We were very happy to see some Foster Grandparents visiting with the residents of one home. Several Agnews family members spoke to us about their closure experience, and we had very honest discussions on the differences between DC and Community care.

The idea of developing a home based on the needs of the individual was mentioned several times – with examples given. All services and supports that the residents need appear to be in place, including health care, dental care, transportation, emergency services, day program, transportation, etc. The importance of family involvement was very apparent, both in the lives of individual residents and in the way that this provider operates overall. I am very hopeful that there will be similar quality placements available for our Lanter man residents in the future. This trip was part of our education on how to make that happen.

Art Lopez

Here are my impressions. I was impressed with the overall quality of the SB-962 homes. The homes were well designed and appeared to meet the needs of the disabled residents that lived there. The homes were equipped with the medical equipment/supplies for the special nursing needs residents. The homes had emergency/backup power for the medical equipment in case of a power failure. The locations of the homes were in quiet neighborhoods and appeared to be centrally located in the community (in close proximity to shopping centers and malls). My observation was that the onsite staff was professional, licensed and experienced in caring for the disabled. The staff to resident ratio was more than adequate and allowed the residents to get more direct (one on one) attention from staff. The in-home day program was done onsite and available for the residents who cannot travel to a community day program. The community day program provided a variety of different activities and allowed the residents choices on the activities they wanted to perform. The service provider was also well-experienced in caring for the disabled and were very impressive.

In conclusion, these are my observations and impressions given what my family member may need in the community. Others may have different needs and may feel that these homes may not meet their family members needs. Also, I do have some concerns given the State’s financial situation that DDS/Regional Centers can provide the same quality of homes in Southern California.

Steve and Gayle McCue

Our trip to San Jose was definitely worthwhile. To visit and learn more about a 962 home was very informative. We were able to get a lot of our questions answered. The home was located in a very fine community that was clean, well maintained and welcoming. The home itself was also clean and well maintained.

The residents and staff were home during our visit, so we were able to observe some of their daily routines and have some discussions with them. This allowed us to get at least a feel for their every day activity which was helpful. We also visited an "Adult Day Program" facility which also was very interesting and informative.

Our only disappointment was that our tour group did not get an opportunity to visit an SRH Home which was our prime interest. Other than that, we were very impressed with the tour and with Elwyn including its employees, operation and mission.
PCC and Elwyn NC managed a tour on homes which Agnews DC clients moved to after Agnews closure. There were about 30 LDC family members who mostly flew from SCA to San Jose on Jan 20\textsuperscript{th}. Elwyn organized the transportation from and to airport. They also provided nice breakfast and lunch at Wyndham hotel. Family members were divided into 6 groups. Each group visited one home for medically fragile clients (962 medical homes), one for behavior challenged clients (SRH homes) and one day program. Although my focus was on the behavior home, I was also impressed by 962 homes. It was like a small hospital in a home. Both types of homes were very organized and nicely furnished.

Based on my previous experiences, usually websites and publications of most companies and service providers give better impressions than the reality. To be honest, my expectation and the reality were very close. Everything seemed to be very well organized both from the way they managed the tour and also the quality of services.

I understand that many LDC families have legitimate concerns and still worry about how transition of their loved ones would affect the services they are receiving at LDC. For many LDC clients who have lived there for decades, the transition will be difficult and may not be as pleasant as they wish to be. It’s clear that LDC closure plan is a reality and will not be changed. I assume that now the energy should be focused on how the comparable fulfilling services could be delivered at the next placement. I believe for those who will not move to Fairview DC, providers like Elwyn and homes like I have observed in Bay area, should be considered strongly. Day programs, leisure opportunities and vocational options are extremely important and should be effectively considered too.

**MingYi Chou**

On January 20, 2011, 26 of us went up to San Jose to visit Elwyn home. We were separated into four groups. My group visited one behavior and two medical homes. We did not see any residents in the behavior home, they all went to the day program, but we saw residents in the medical homes. All the homes look new and clean, well maintained. We talked to the staff, asking some questions etc. They gave me a good impression on the initial visit. Looking from their operation and staff they hire I believe there must be experienced management behind them. According to Mr. Kottke, director of Elwyn NC, at the present time they have contract with East LA RC to develop 8 such homes in San Gabriel Valley. I recommend anyone interested should go to websites to learn more about Elwyn and pay them a visit personally. What I have missed on my trip was my group didn’t visit their “day program” and we did not see any residents in behavior home.

**Phyllis Elijah**

I thought the homes we saw were first rate. The staff seemed competent and the residents seemed content. I did not see a home that was suitable for a person with PICA problems (putting things in mouth) due to the amount of decorations and other nice trimmings on the homes.

I think the thing that impressed me the most was that these homes where staffed around the clock with awake staff on three shifts, not two live in people that would be asleep part of the time and also the staff level of training/licenses and experience with Agnew residents.

The homes were also well designed and constructed, especially the ones the built from the ground up.

**Carolyn Lewis-Lugan**

It was a great privilege to go to Northern California to see the Agnews homes. The Elwyn Company was kind and gracious to us. The group I was with visited three of these homes; two medical models and one behavior model each home was warm and inviting.
In the two medical models I found them beautifully maintain. The newest and the best equipment were in every room. The Staff members were more like caring family members. The small number of residents per home was wonderful and lends to what appears to be a more caring atmosphere. The rooms were large and quite comfortable; the bathrooms were specially customize for easy accessible to anyone and all the doorways were extra wide. Many staff members that were previous employees of Agnews are part of the staff for many of these homes.

At the behavior home the residents were away to the Day Program. We saw individual resident self decorated bedrooms. The community rooms/common areas were cozy and warm.

On the scale from 1–10, I would give the homes I saw an 8. These were very good placements and could honestly say equal to and in some respects better than. But I need to say there is not a placement appropriate for my sister; she would need a home with both medical and behavior model which at this time is not available.

Dorothy Diamond

I was able to go with a group of PCC members to view two medically fragile and one behavioral home that Elwyn has built and Agnew's consumers have been living in for the past three years. I was surprisingly encouraged to see how well things were running and the services that were being offered in these homes.

The first home we saw was a behavioral home. There were no consumers in because they were at their Day Program. Their home was an open area concept with extra wide bedrooms doors & extra large bathroom so if the need should arise in the future for wheelchairs or for any medical needs the consumers will not have to ever move. The ratio is 3 staff to 4 consumers during waking hours. No alarms were on the doors because no one tries to run a way but if they needed alarms they would have them. They have extra staff on the weekends to help consumers with activities.

Medically fragile homes, 962, have 4 to 5 consumers to 3 staff on am, pm and 2 awake on NOC shift. The lead person for each shift is either a licensed RN or LVN with licensed physic tech. At one of the 962 homes they employed a CNA on the am shift. If the need should arise for more staffing because of illness or outings they can arrange for more. The house administrator is a RN that takes care of two homes working a 40hr. week.

The 962 homes we saw all had wheel chair consumers with 2 g-tubes, had open area concept housing with living, dining and kitchen areas. Bedrooms were large to accommodate all of their furniture and have doors leading to the outside for safety issues. The houses have covered patios so they could go out and enjoy the fresh air. There back up system is 6 batteries that run for10 hrs and then a gas generator to plug in the batteries for recharging. They check this back up every 14 days. Each bedroom and bathroom is equipped with a ceiling lift. I feel that these are safer because then no electrical cords can obstruct the moving of a consumer. There were recliners in the living spaces with seat belts so they could sit, recline and enjoy TV, movies etc. without being in a wheel chair all day. One 962 home keeps a room available for a consumer who might need IV’s or to recuperate from a hospital stay and then returns to their home. They had alarms on the doors and windows but I did not feel the alarm sound was loud enough to hear.

If the need arises for x-rays or blood work a vehicle comes to the house to do the work. The allotted time for them to come is 4 hrs. I feel that this is a suitable time frame. The RN does the assessment on a consumer to see to their medical needs and reports to the doctor. The doctor comes once a month or more if needed. If he can not make it to the house within a reasonable time they take them to the doctor’s office. Medical emergencies they call 911. Doctor admits to the hospital, does not work at the hospital but is in contact with them. Any specialist that is needed will be provided
psychologist, respiratory therapist, physical therapist etc. As of now, dental still has a problem providing services in the community and they are constantly working on improving the situation.

We visited one home during lunch so we were able to observe there routine. Some parents and foster grandparents were there helping with the feedings. I appreciated seeing that parents were allowed to openly help with their family member and foster grandparents are encouraged to come. A dietician comes in and goes over the menu for the month with staff, instructing them what consumers should be eating, how to prepare or what type of food to give to a g-tube consumer. Staff is in charge of house hold chores, laundry, grocery shopping etc. They give instructions to consumers who would like to participate on cooking or just watch. Staffs that I talked to (some from Agnews) said they enjoy this home atmosphere and were glad they could go with Agnews consumers. One home was doing their day program with the instructor working on Valentine Day decorations. He comes in from 7:30 to 4. He had worked at Agnews and finds it pleasurable working in a home atmosphere with a smaller group.

Some of the day trips they have taken were local museum, movies, libraries, malls, walks etc. They also go to church on the weekends. One week they go to one denomination and the next to another. The congregations have openly welcomed them into their churches. One home was situated in a cul-de-sac and they participate in all the block parties. They have attended 4th of July and Halloween.

At this time there is only 1 van per home for outings or doing what ever is needed. They would like to have fundraisers to earn money for more vans. They may borrow another homes van if they are not using it so all consumers may go to an outing together and there is a stand by van always available to accommodate anyone else’s needs if an emergency should arise.

The parents that we talked to all said that community placement was not what they had wanted for their loved one but were willing to give it a try and now they speak very highly of having good experiences by being in the community. One behavioral consumer’s mother said since her son has been in the community he has blossomed because of the smaller group situation. Another parent was happy that their loved one was much closer so they could visit anytime and participate in outings and activities that go on in the house.

I think that it was a positive experience of what can be accomplished in the community. There are still questions to be asked for services that my son needs but everyone has to find the right home and services for their own loved one whether it be community or a Developmental Center. With communication I am hoping to find the best solution for my son.

Robert Hazard

On January 20, I was fortunate to be able to participate in the organized tours of some of the community homes established and run by Elwyn in the Bay Area. Here was an opportunity to see first-hand what some of the newer community homes are like. I went with mixed views on just what was right for my sister: a developmental center or a group home in the community. For most of her life, beginning at age 7, my sister has lived at Lanterman. She has received excellent care by qualified and experienced staff. Because of that, I became actively involved in the PCC. I strongly felt that Lanterman, as a state run developmental center, provided the best care for my sister.

Being a member of the VOR, the PCC and an active member of my sister’s residence group, I was being informed by dozens and dozens parents and family of the horror stories experienced in the community. Arriving at Lanterman brought relief, consistent and quality care for their loved one.

With the impending closure of Lanterman, all of the families at Lanterman will be faced with the decision as to where there loved one will be moved to for perhaps the rest of their lives. We should all
be prepared to make the best decision with an open mind and with the first-hand experience of seeing all of the alternatives. I’ve seen life at Lanterman, Agnews, Fairview, Camarillo, and Sonoma, and now I’ve seen several homes in the community run by Elwyn.

Being divided into five groups, depending on our needs, skilled nursing homes or behavioral, we toured 3 facilities. Our first stop was a very attractive, new looking home in a nice neighborhood in San Jose. This particular home was one of the “962” medical homes. Upon entering the house, I was immediately impressed by the spaciousness, cleanliness, and how well it was equipped to care for their 5 residents. There were modern track hoists in the ceiling to conveniently transport the patients from room to room, whether it is the living room, bathroom, shower, or dining room. Each resident had their own specially equipped wheelchair, just like they had from Agnews.

The staff was equally impressive. What I liked about the arrangement was that about half of the staff was from Agnews and half was Elwyn trained. It was a very symbiotic and team-oriented relationship. If we do indeed move in the direction of community placement, our Lanterman staff should be encouraged to participate in the State Staffing Program. The homes are owned by the Housing Trust which makes them a permanent home for the residents.

The second home we visited was a behavioral home, one that my sister would be most suited for. It too was new, clean, well laid out and staffed by the same mix of developmental center and Elwyn trained staff. I took the time to talk with the DC staff about their experiences working there for the past few years. They loved it! The atmosphere, conditions, camaraderie, and organization were very enjoyable. We were informed that there were no formal or informal complaints from the neighborhood. Since the homes were required to have emergency equipment and supplies on site, this was a plus for the neighbors.

Our other stop was to the Mission Bay Works day work facility. Here, 135 clients, who are able to, are proud to make a positive contribution to the community. Wilma, the Program Director, had 21 years of experience working at Agnews. It was very gratifying to see so many state employees happily working in the community with the folks that they have been caring for so many years. The “family” has been able to stay together.

We finished off the day with all of us meeting back at the local hotel meeting room discussing and asking any final questions. Bottom line, we were impressed. The bar has been set with Elwyn. Having over 150 years of progressive experience in caring for developmentally disabled people puts Elwyn about 20 years ahead of most of the California community homes. There are other options available: other community group homes, Fairview DC, or perhaps even keeping Lanterman open. You will be best prepared to make your decision if you have examined all of the choices.

**A Copy of the Lanterman Closure: Rights and Remedies is available for PCC Members**

This legal review of the Lanterman Closure Plan was prepared for the PCC, and outlines some of the individual and collective rights of Lanterman residents and families. It is available to PCC members only. If you have not yet picked up your copy in person or requested that it be mailed to you, please contact the PCC office at ldcpcc@gmail.com, 909-444-7572 or by mail at PO Box 4408, Diamond Bar, CA 91765
The PCC welcomes interested residents, families and Lanterman staff to attend all meetings. Contact the PCC office for information on meeting dates and times.

The Contact, PCC Post, and the Website -- The Parents Coordinating Council communicates regularly with all Lanterman families and others who have shared their contact information with us, regardless of whether or not they are PCC members. We honor the privacy of all families and do not share any contact information given to us. The Communication Committee greatly appreciates everyone who helps us with the following methods we use to distribute information:

The **PCC POST** is a one-page emailed update sent out on most Fridays that gives condensed information on what has happened in the past week and what is coming up. This format allows us to get information out on a regular (and inexpensive) basis without waiting for the Contact to be published. People who do not have email or who do not get the **PCC POST** by email receive the past issues with their mailed **Contact**.

The **Contact** newsletter is mailed every 4 to 6 weeks. It contains articles and information on prior and upcoming meetings, important issues facing Lanterman, and updates on resident activities. It is designed to help family members who may not be able to visit Lanterman or attend meetings regularly keep in touch with what is going on.

[www.lantermanpcc.org](http://www.lantermanpcc.org) is our website address, where past issues of the Contact and the PCC POST may be found, along with meeting minutes, family resources, important links, newspaper articles, etc.

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The PCC newsletter is meant to educate families. All articles herein are the opinion of the authors.

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