



# Prader-Willi Family Newsletter

## Summer Edition



### Endocrinology Corner: PWS & Puberty

By Dr. Sejal Kadakia

We have noticed that there is often anxiety in parents of our children with PWS regarding puberty and hormone replacement. For the parents of our younger children, we'll talk today about what to expect.

Estrogen and testosterone are very important for the health of our bones and this is the main reason that we recommend hormone replacement when puberty does not start or stalls. This is exactly why older women and men (who have lower levels of these hormones) are at higher risk of fractures.

For girls, estrogen is given via either a transdermal patch (sticker) or oral pill. The patches offer more physiologic (natural) replacement of estrogen, but we know that many children with PWS will not tolerate a patch on their body. For boys, testosterone is given as a subcutaneous (under the skin) injection, usually once every 4 weeks to start and later increased to every 2 weeks. At higher doses of testosterone, a gel is available, but this may not be appropriate for all boys with PWS as strict hygiene is required as to not accidentally expose others in the household.

We aim to mimic normal puberty. Estrogen and testosterone are started at very small doses and increased approximately every 6 months. For girls, once an initial menstrual period is had (usually within 2 years), a second hormone, progesterone, is added. Birth control pills have both estrogen and progesterone and are often used at that point as they are convenient. Once a girl is menstruating, if we can tailor the treatment to allow for just a few periods a year, if there are concerns such as with hygiene.

We are only replacing a hormone(s) that the child's body is not making. Our goal is to have normal timing and speed of puberty. This is very different than the "hormonal replacement" given to older individuals.

We will start talking to you about puberty once our child is in their pre-teen years (sometimes earlier). Please feel free to ask questions at your next clinic visit with us – there is only so much information we can fit here in this newsletter!

### CHOC Family Recipe Corner

With every issue of our PWS newsletter, we want to share a recipe suggested by one of our Prader-Willi families. Consider sending healthy, low calorie and delicious ideas to Laura Clapper, RD at [Lclapper@choc.org](mailto:Lclapper@choc.org).

#### PROTEIN "MUFFINS"

Recipe submitted by Stella's mom. Each "muffin" has fewer than 50 kcals.

#### Ingredients

- 2 cups spinach, chopped
- 1 small red pepper, diced
- 1 roma tomato, diced
- 2 cups egg white
- Salt and pepper

#### Directions

1. Preheat the oven to 350°F
2. Lightly grease a muffin tin with vegetable spray.
3. Divide the spinach across the cups equally.
4. Fill the cups with tomato, red peppers and egg whites.
5. Season with salt and pepper.
6. Bake for 15 minutes, or until the whites have set.





## Behaviorist's Corner: Transition of Care

By Dr. Peter Chung

Transition of care has become an area of increasing focus in pediatric medicine, particularly for chronic and complex disorders like Prader Willi Syndrome (PWS). Medical and educational support and treatment of children often includes a large, multidisciplinary team that provides a family-centric approach. However, for adults, much more is often expected from the individual to coordinate and communicate between different specialists, and the general support provided by the system decreases. Just as graduating from the public school program and going "out into the real world" can be a difficult transition, graduating from a pediatric clinic to an adult provider can be a challenge. This recent article ([www.mdpi.com/2077-0383/10/9/1991/pdf](http://www.mdpi.com/2077-0383/10/9/1991/pdf)) from Switzerland demonstrates that transitional care is just as difficult in other nations as in the United States. The authors discuss their approach to transitional care, which includes a "checklist" of information that is discussed at team meetings between the pediatric and adult provider. The authors also discuss how important (and difficult) it can be for adults with PWS to maintain control of food intake, keep up with physical activity, and adapt to work environments. Their report adds to the growing literature on how to improve transitional care for the PWS population.

California has a number of support systems in place for adults with PWS.

- While individuals are still enrolled in school, the school should create an individualized transition plan to help the student prepare for life after school. More information about transition plans can be found here: <https://serr.disabilityrightscs.org/serr-manual/chapter-10-information-on-transition-services-including-vocational-education/>
- Many individuals will have already been qualified for Lanterman services through their local Regional Center ([www.dds.ca.gov/rc/](http://www.dds.ca.gov/rc/)). Qualified individuals can receive supportive services to help them improve their quality of life and independence.
- Another resource to investigate is the Department of Rehabilitation ([www.dor.ca.gov/](http://www.dor.ca.gov/)). The department's focus is to help individuals with disabilities in employment, independent living, and equality. They even have a branch of student services that can open cases in individuals as young as 16 years.
- California law allows for parents of individuals with developmental disabilities to obtain limited conservatorship ([www.courts.ca.gov/selfhelp-conservatorship.htm?rdeLocaleAttr=en](http://www.courts.ca.gov/selfhelp-conservatorship.htm?rdeLocaleAttr=en)). With this process, parents can retain some of the decision making rights (e.g. financial, educational medical) even if their child is over 18 years old. This process may be suitable for some and not for others. You can find more information about conservatorship and alternatives to conservatorship here: <https://pwcf.org/wp-content/uploads/2020/01/Conservatorship-FAQs.pdf>
- The Get Safe USA program ([www.getsafeusa.com/about](http://www.getsafeusa.com/about)) provides education and training about safety in the physical, mental, emotional, and cyber domains.
- The PEERS program ([www.semel.ucla.edu/peers](http://www.semel.ucla.edu/peers)) is a social skills program developed at UCLA for individuals with autism spectrum disorder. Some individuals with PWS who struggle with socialization may benefit from participating in this program, and certified providers can be searched for on the PEERS website. Newer developments include programs with a focus on careers and the workplace, and research is being conducted to see if these programs are effective.



## Social Work's Corner: Conservatorship

By Bobbi McGann, CSW, MS

If your child is developmentally disabled and will not be able to make medical decisions and care for themselves independently upon reaching the age of 18, you will need to go through a legal process called Limited Conservatorship.

The person chosen by the court to be a conservator will have their responsibilities described in their "Letters of Conservatorship" and in the court order appointing them. These responsibilities may include: arranging for care and protection, deciding where the young adult "conservatee" will live, being in charge of health care, food, clothes, personal care, housekeeping, transportation, recreation.

If you are going to file a conservatorship petition for an adult or soon to be adult with developmental disabilities and you do not have a lawyer, you may consider one of the resources below.

CHOC's Legal Clinic can assist with conservatorship for low-income families in any county. Contact your CHOC Social Worker or call the Social Services Department at (714) 509-8521 to see if you meet the financial eligibility and to schedule an appointment. If you do not meet financial eligibility, a list of referrals is also available.

The Orange County Superior Court offers a free conservatorship clinic the 1<sup>st</sup> Monday of every month from 9-11:00 AM. Attendees are assisted on a first-come first-serve basis. The clinic is located at the Central Justice Center, 700 Civic Center Drive West, CA 92868. Room 100-A.

Visit their website for more information: [www.occourts.org/self-help/probate/index.html](http://www.occourts.org/self-help/probate/index.html)

Community Legal Aid SoCal is another source of information. You can submit a request online at [www.communitylegalsocal.org](http://www.communitylegalsocal.org) or call 800-834-5001 or 714-571-5200 **to request assistance with conservatorship.**

In Los Angeles County, Bet Tzedek offers a Self-Help Conservatorship Clinic on Mondays. Check-in begins at 9:15am and assistance is offered on a first come first served basis. 301 W. 1<sup>st</sup> St Los Angeles, CA 90012. Bet Tzedek legal clinic can be reached at: 323-939-0506.

In Riverside County, Riverside Legal Aid offers free services [Riversidelegalaid.org](http://Riversidelegalaid.org) or 951-682-7968.

Additional information and assistance with the conservatorship process may be obtained from your Regional Center worker, your school Transition counselor, or CHOC Social Worker. Please call the CHOC Social Services Department at 714-509-8521 with any questions or concerns.

### Lawyer Referral Conservatorships and Guardianships:

Orange County Bar Association Lawyer Referral and Information Services (LRIS)

P.O. Box 6130. Newport Beach, CA 92658

(949) 440-6747 or (877) 257-4762

\*Services provided by Orange County Bar Association. Connects clients with local qualified attorneys.

The Law Office of Diamond Tran

10061 Talbert Ave. Suite 221. Fountain Valley, CA 92708

(714) 916-8726 | Email: [diamond@diamontranlaw.com](mailto:diamond@diamontranlaw.com)

\*Speaks Vietnamese

Bet Tzedek

Los Angeles Self-Help Conservatorship Clinics

(323) 939-0506



## Social Work's Corner: CURATELA

By Bobbi McGann, CSW, MS

Si su hijo(a) tiene discapacidades del desarrollo y no es capaz de tomar decisiones médicas y cuidarse por sí mismo de manera independiente al cumplir 18 años de edad, usted tendrá que iniciar un proceso legal denominado curatela (*conservatorship*).

La persona asignada por el tribunal como el curador tendrá sus responsabilidades descritas en una "Carta de curatela", igual que una orden judicial indicando su designación. Las responsabilidades pueden incluir: coordinación del cuidado y protección, elección de dónde vivirá el joven bajo curatela, estar a cargo del cuidado médico, alimentos, ropa, higiene personal, tareas domésticas, transportación y diversión.

Si piensa tramitar la solicitud para curatela de un adulto o una persona que pronto será un adulto con discapacidades del desarrollo y usted no tiene un abogado, es posible que sea idóneo para recibir ayuda legal gratuita.

La clínica legal de CHOC Children's puede ayudar con la curatela para familias de bajos recursos en todos los condados. Ud puede llamar al departamento de servicios sociales de CHOC al 714-509-8521 para más información sobre la lista de espera. Si no califican con los requisitos financieros, también hay disponible una lista de referencias de abogados privados.

El tribunal superior del condado de Orange ofrece una clase gratuita acerca de curatela el primer lunes de cada mes de 9 a 11 AM. Se les ofrecerá ayuda a las personas que asistan en el orden que se presenten. La clase se realiza en el centro "*Lamoreaux Justice Center*" que se localiza en el 341 The City Drive, 7º piso, Orange, CA 92868.

Community Legal Aid SoCal ayuda con consejo legal y información sobre el proceso. Se Localiza en el 2101 N. Tustin Ave Santa Ana, California 92705. Están abiertos 9-5, Lunes a viernes. 800-834-5001 o 714-571-5200.  
[www.communitylegalsocal.org](http://www.communitylegalsocal.org)

En el condado de Los Angeles, Bet Tzedek ofrece una clínica cada lunes. Empieza a las 9:15 y ayudan a la gente en la orden que llegan. 301 W. 1<sup>st</sup> St Los Angeles, CA 90012. 323-939-0506.

En el condado de Riverside, Riverside Legal Aid ofrece servicios gratuitos. [Riversidelegalaid.org](http://Riversidelegalaid.org) o 951-682-7968  
Información y ayuda adicionales acerca del proceso de curatela se pueden obtener a través de su coordinador del Centro Regional o el asesor de transición escolar.

Si tiene preguntas, por favor, llama al departamento de servicios sociales al 714-509-8521.

## Dietician's Corner: Limiting Access

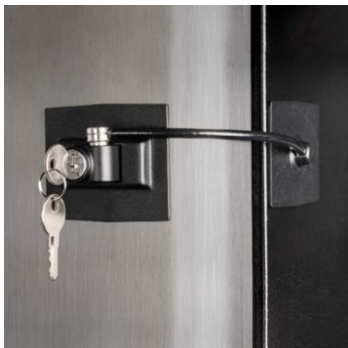
By Laura Clapper, RD

The desire to sneak food is a natural part of Prader Willi Syndrome. As a caregiver, the goal is to provide structured, healthy, well balanced meals. Foods consumed outside of these mealtimes often leads to unwanted weight gain. Limiting access to food between meals can be a challenge, so most of our CHOC families use locks in the kitchen. Since our PWS kids are very clever when it comes to finding food, we have compiled a list of effective deterrents.

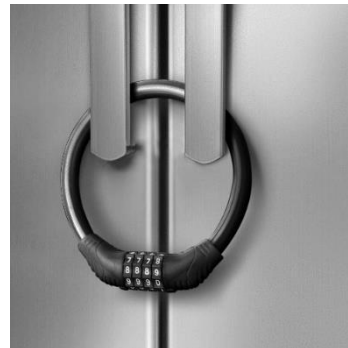
These are some examples of what we found on Amazon but can be found in other stores and websites as well.

Disclaimer: All information posted is merely for educational and informational purposes. CHOC Hospital is not endorsing the below products or websites, should you decide to proceed to act upon any information on this website, you do so at your own risk. While the information on this website has been verified to the best of our abilities

Guardianite Premium Key Lock \$18



Fresheracc Combination Lock \$13



Urban August Combination Lock \$10



Securefrig Magnetic Lock, \$154-\$282



Computer Security Products Key Lock \$20

