PRESIDENT’S MESSAGE

Hi All -
Welcome to our Spring 2012 newsletter. I hope it finds everyone well.

The San Francisco Bay Area Chapter has had an action packed start to 2012. We kicked off the year with a winter fun day where about 40 of us bowled in San Francisco at the Yerba Buena Skating and Bowling Center. Donna and Harold Weaver hosted a packed “Over 21” dinner out. It was at Zarzuela Restaurant where Julia Jara’s father kept us well supplied with sangria and tapas.

A few weeks ago we had the annual springtime gathering, hosted by the Parkhurst Family. Over 50 people came out for good conversation, arts and crafts, and an egg hunt. Looking ahead, we have an exciting line-up of events coming up, which are listed below. And we are taking this opportunity to share some new and exciting research on achondroplasia.

Lee

MARK YOUR CALENDARS!

- **April 28th 12-4:00 pm** – Lake Chabot Marina Picnic
- **May 27th 12:00-4:00pm** – Memorial Day Sports and Pool Event, hosted by Joel & Marcia Lusk
- **June 15-20th** - Painted Turtle Camp, Lake Hughes, CA
- **June 29- July 6** - Dallas National Conference
- **August 4, 1-4 pm** – Pool Party hosted by Uniacke/Wiser family
- **Sept 7-9th** -- Camping at Big Basin, hosted by Sue Larkin
- **October 5-7** – Regional LPA Conference, Las Vegas, NV

If you would like to host an event please send a message to:
[LeeUniacke@gmail.com](mailto:LeeUniacke@gmail.com)

EMERGING RESEARCH AND POTENTIAL TREATMENTS IN ACHONDROPLASIA

*Excerpted from an article by Ericka Okenfuss, MS, Lifetime LPA Member, Medical Resource Director, Medical Advisory Board Member*

With the discovery of the genetic causes for many of the skeletal dysplasias (forms of dwarfism), much research has been dedicated to understanding how the specific genetic mutations affect bone and its growth. Making bones grow in individuals with skeletal dysplasias is not just about final adult height, but also reducing the medical complications that often come along with dwarfism. The purpose of this article is to help inform LPA members on the current research and how it may affect us in the near future. As achondroplasia is the most common form of dwarfism, it will be the primary focus of this article. That being said, there is research
being done on some of the other more common skeletal dysplasias, such as diastrophic dysplasia, pseudoachondroplasia and spondyloepiphyseal dysplasia congenita that will likely lead toward a better understanding of these conditions and the development of potential treatments for them in the not-so-distant future.

**What individuals and groups are leading the research efforts?**
There are researchers here in the United States and in other countries who are studying how mutations in the FGFR3 gene causes decreased bone growth in achondroplasia. One such group is BioMarin, a pharmaceutical company based in California. There is also a non-profit group, Growing Stronger, started by an LPA family, that is raising money to increase research on understanding the underlying biology in achondroplasia.

**What is BioMarin hoping to do for individuals with achondroplasia?**
BioMarin has developed a drug that they believe will increase bone growth in individuals with achondroplasia. They hope not just to see growth in the bones of the arms and legs, but also in the spine, skull, face, chest and other bony areas of the body that contribute to medical issues in achondroplasia. With potential growth in these other bones, they hope to see a decrease in the serious complications of achondroplasia, such as spinal stenosis, foramen magnum (opening at the base of the skull) stenosis/compression, obstructive sleep apnea and ear infections.

**How does the drug work?**
In order to understand this, we need to know how the achondroplasia mutation in FGFR3 affects bones. FGFR3 is a receptor (a protein on the surface of the cell) that regulates bone growth. Its specific role is to slow down bone growth and balance out the effects of other receptors and molecules that promote growth. Think of these as the red and green lights of bone growth. FGFR3 is a red light. When it is “on,” bone growth slows or stops. When it is “off,” bone growth can go or accelerate. The mutation that causes achondroplasia causes FGFR3’s red light to be turned on too much of the time causing less bone growth than someone without the mutation. BioMarin’s drug is a molecule that works in the same pathway as FGFR3. Their drug, called BMN-111, has been shown to block the effects of too much signaling from the achondroplasia FGFR3 mutation. The idea is that adding a green light to the growth pathway of FGFR3 will hopefully make growth closer to average.

**What does the drug do in animals?**
In mice with achondroplasia, BioMarin reported that BMN-111 “restored normal growth.” The drug affected all of the bones affected by achondroplasia, not just the bones of the limbs. They saw growth in the spinal canal and the foramen magnum and changes in the shape of the head and face of the mice. BioMarin also showed that this drug increased growth in animals not affected with dwarfism.

**What is the current timeline for the testing and marketing of this drug?**
BioMarin is currently testing the BMN-111 drug in average statured adults to determine if it is safe for humans. Once it is considered by the FDA (US Food and Drug Administration) to be safe, BioMarin intends to begin a trial in children with achondroplasia. They hope to start this in late 2012 or early 2013. In the study, children with achondroplasia will either receive the drug or a placebo for 12 months. During that time, the patient would be evaluated for changes in growth, their proportions (by measurements), the way the bones look on x-rays, the size of the foramen magnum and other parameters. If
the first phase proves the drug is safe and there are no serious side effects noted in the initial months of the second phase, BioMarin hopes to start testing the effects of this drug on the foramen magnum in babies with achondroplasia who are at highest risk for this complication.

**What don’t we know about this drug?**
- If it is safe in humans.
- If it can be tolerated by children.
- If it will cause any significant changes in the growth and development of a child with achondroplasia

**If this drug works, what might it be able to do?**
It could reduce the medical complications of achondroplasia. It could:
- increase overall height.
- enlarge the foramen magnum and the spinal canal.
- allow the long bones to grow at a similar rate and therefore be straighter.
- increase the growth of the face and reduce sleep apnea and ear infections.

**What is being done to support research in achondroplasia and skeletal dysplasias?**
Because each skeletal dysplasia (form of dwarfism) is a rare condition, there is not a lot of funding from institutions such as the National Institutes of Health. LPA does not fund or support medical research as part of its mission, as other support groups for specific genetic diagnoses often do.

A new non-profit organization, Growing Stronger, has been recently founded. Its mission is to “improve the quality of life of little people through supporting research.”

**Note from LPA:** Little People of America does not endorse the work of BioMarin or any related company that pursues dwarfism research. At this time, LPA’s goal is to stay updated on these activities and to keep the membership informed. As more information about such research becomes available, LPA plans to develop position papers related to research developments.

(Full article can be found in LPA Today.)

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**Book Review**

*You’ll Grow Soon, Alex* by Andrea Shavick & Russell Ayto.

*You’ll Grow Soon, Alex* is an endearing story about a short boy who wishes to be tall. He wishes to be tall more than anything else in the world. In fact, he wants to be tall so badly that he asks his mother, father, sister, and teacher for suggestions on how to grow. They each give healthful suggestions such as eating protein or exercising more, but none of it works. Finally Alex asks his very tall uncle for advice. His uncle teaches Alex that growing is not about growing in feet and inches, but rather about opening one’s heart and growing on the inside.

Have you read a good book that addresses issues pertinent to Little People? Would you like to share your review? Please send your submission to Keren Stronach at keren@eaconsult.com
Dwarf Tossing in Florida
Legislation in Florida (House Bill 4063) that would have enabled bars in Florida to, once again, host Dwarf Tossing events has been successfully fought off, thanks in part to the LPA’s community rally against the bill. In addition to signing petitions and making phone calls, LPA members visited the Florida capitol to protest the new legislation. When the bill was first introduced, supporters of the legislation argued that Dwarf Tossing has no direct negative impact on the dwarfism community and only affects those who participate. LPA strenuously objects, contending that dwarf tossing endangers the individuals who participate, objectifies and degrades Little People, and perpetuates negative stereotypes. Rather than limit the liberties of any citizen, the ban on dwarf tossing protects the health and welfare of the community at large. LPA is gratified that its rallying cry was heard and dwarf tossing is where it should be – tossed out of committee.

Spanish Link On-Line
LPA finally has a Spanish link on-line!! If you are a Spanish speaker, go check it out, and, if not, please refer any Spanish speaking individuals to this link. It has an LPA membership registration form, as well as a few of the Natural Histories written by Dr. Richard Pauli. The goal is to continue adding to the website to ensure access to our Spanish speaking population.

LPA Bay Area Chapter Business Cards
Have you ever met a Little Person on the street and wanted to hand out a card to let them know about our LPA chapter and its activities? Well, they are now available. You can obtain the LPA Bay Area Chapter card, which has both the national and local chapter websites as well as room to add your own personal contact information by contacting our very own chapter President, Lee Uniacke at lee@kongregate.com.

THE PAINTED TURTLE CAMP FOR KIDS AGES 7-16
Saturday-Thursday, June 15-June 20th
Lake Hughes, CA, www.thepaintedturtle.org

The Painted Turtle is accepting applications for the Skeletal Dysplasia and MPS Summer Session to be held June 15-June 20th. Summer Camp provides an opportunity to meet and connect with other Little People in a supportive and fun environment. Campers will enjoy boating and fishing, arts and crafts, woodshop, music, and much more! Doctors and nurses are available at the site all week to take care of any medical needs campers might have while at camp. The Painted Turtle is located in Lake Hughes in the Antelope Valley, 40 miles north of Los Angeles. It’s a beautiful facility with a fully equipped medical center and temperature-controlled cabins with private baths. All meals are provided and served in the dining hall overlooking the lake.

There is no cost for campers to attend this program Summer Camp is for campers.
• A bus will be available to provide transportation to and from The Painted Turtle and the Burbank Airport.
• For more information please visit the web site, www.thepaintedturtle.org.
NATIONAL CONFERENCE
DALLAS, TEXAS – JUNE 29-JULY 6TH

The National LPA conference this year is hosted by the Dalworth Chapter and will take place at the Sheraton Dallas Hotel in Texas from June 29th to July 6th. The national conference provides a unique opportunity to meet and connect with LP from all over the United States and beyond, to get information about dwarfism, participate in the Dwarf Athletic Association of America (DAAA), and have lots of fun.

In order to register, go to the National LPA website, www.lpaonline.org to download the registration guide and mail it in or complete it on-line. Once you have done so, you will receive your LPA Conference Receipt Code, which you will need in order to make your hotel reservation at the Sheraton Dallas Hotel. If you need more than one hotel room for a large family, please contact the LPA office at 1-888-LPA-2001 or info@lpaonline.org.

Future National conferences:
2012 - Dallas, Texas, Sheraton Dallas Hotel, Sat. 6/30 - Fri. 7/6
2013 - Washington, DC, Marriott Wardman Park Hotel, Sat. 6/29 - Fri. 7/5
2014 - San Diego, CA, Manchester Grand Hyatt Hotel, Sat. 7/5 - Fri. 7/11
2015 - St. Louis, MO, Hyatt Regency St. Louis, Sat. 7/4 - Fri. 7/10
2016 - Boston, Massachusetts, Sheraton Boston Hotel, Sat. 7/2 - Fri. 7/8
2017 - Denver, CO, Sheraton Downtown Denver Hotel, Sat. 7/1 - Fri. 7/7

MEMORIAL DAY SPORTS AND POOL EVENT
Sunday, May 27th 12:00-4:00 PM
Aquatic Park, 4455 Black Ave., Pleasanton
Hosted by the Joel and Marcia Lusk

Join us for fun day of sports, swimming, and hanging out. This is a day for everyone - from toddlers to adults! Activities include soccer, baseball, Frisbee, swimming, climbing play structures, eating pizza and lounging around in picnic chairs.

For more information, contact Joel and Marcia Lusk, jmlusk@gmail.com or 510.877.0556.

What to bring: Drinks or snacks to share, chairs or blankets to sit on, swimming suits, towels, and sunscreen for swimming in the Aquatic Pool.

Directions From Hwy 580:
Exit Santa Rita Road south, follow for about 1-2 miles past 6 or more lights, turn right on Black Ave. after Valley. The Aquatic Center is on your right. Turn right at the second driveway, to drive behind the Aquatic Center. Follow the driveway around to the park area.

From 680:
Exit at Stoneridge Ave, one exit south of the 580 interchange, and head east. Follow Stoneridge for 2 or 3 lights until Hopyard Ave, and turn right. Follow Hopyard past 2 lights (West Las Positas and Valley) and turn left at the next light, Black Ave. Follow Black Ave. almost to the end. About 200 yards before Santa Rita Road, look for the Aquatic Center on your left, turn into the parking lot and go behind the Aquatic Center to the park area.
POOL PARTY
August 4th from 1:00-4:00 PM
136 Ward St., Larkspur, CA
Hosted by the Weiser/Uniacke family

Join us for an afternoon of fun in the sun, good food, and great company at the beautiful home of the Weiser/Uniacke family. Keep an eye out for the Evite, which will have more information and directions.

What to Bring: snack to share, bathing suit, towel and sunscreen.

For more information contact the Uniacke-Weisers at 415 924-6914 or sharisharishari@gmail.com

Directions:
From San Francisco: Take 101 north to the Tamalpais/Paradise Drive exit (Corte Madera/Larkspur). Turn left at the traffic light onto westbound Tamalpais Drive. Continue approximately 1 mile (road will curve to the right and to the left). Turn right onto Corte Madera Ave, which changes name to Magnolia Ave at Larkspur's border; continue approximately one mile on Magnolia Ave. into downtown Larkspur. At the first stop light turn left onto Ward St. (Left Bank Cafe is at this corner). Continue 1 1/2 blocks to 136 Ward Street. House is on right.

From the East Bay:
Take the Richmond/San Rafael Bridge, exiting at the Sir Francis Drake exit 1/2 mile past the bridge. Continue on Sir Francis Drake Blvd. for approximately 1 1/2 miles, passing the Larkspur Landing shopping center, passing under highway 101 (be in the left lane at this point). Take the southbound entrance ramp to 101; remain in the right lane and exit immediately at the Lucky Drive exit onto Fifer Drive. Continue on Fifer through traffic light. Turn left at the end of Fifer onto Lucky Drive. Turn right at stop sign onto Doherty Drive. Turn left onto Magnolia Ave. Drive 1/4 mile into downtown Larkspur. Turn right onto Ward St. (at the Left Bank Restaurant). Continue 1 1/2 blocks to 136 Ward Street. House is on right.

CAMPING AT BIG BASIN
September 7-9th, 2012
hosted by Sue Larkin

Enjoy two days of star gazing, campfires, hiking, tree hugging, and whatever else catches your fancy. Most of all come to enjoy good company in the great outdoors. You can either pitch a tent or stay in the comfortable tent cabins that come equipped with beds and a wood stove.

For more information, go to www.bigbasin.org or contact Sue Larkin at susanlarkin@hotmail.com or (408) 369-9518
Past Events

A big THANKS to the Zembsch family for hosting the Holiday party at their house, arranging a visit by Santa and the red hot fire engine crew, and ensuring that fun was had by all.

Bowling at Yerba Buena in San Francisco
Thank you to Robert Hamill for organizing the Winter Fun Day in San Francisco. Members of our chapter had a great time bowling and hanging out! As promised, fun was had by all.

LPA Spring Party
A big thank you is due to the Parkhurt family for opening up their lovely home, yet again, and hosting us all to a wonderful gathering, an Easter egg hunt, a great array of games for kids, tables laden with delicious food, and more....
**504 Plan Versus an IEP**

Adapted from a piece by Leslie Granshaw, a Special Education Teacher in the State of NY.

**Question:** We were informed today that our son would be put on a 504 versus an Individualized Education Program (IEP). We would like to understand the differences between these two programs.

**Answer:** 504 plan is a plan that is developed if a child has a disability but does not require special education services. The 504 plan allows your child to participate in certain activities and not be discriminated against due to his or her short stature.

An IEP is developed when a child has a disability and needs special education and related services. For example, if the child is two grade levels below in reading and math, this may constitute a Learning Disability and will allow the child to have support services that are tailored to his or her needs.

When you talk to the school, make sure to ask questions and get the information you need so that you can best advocate for the well-being of your child. Remember that it is the district’s job to provide your child with a SAFE environment.

If walking from the bus to the class or between classes is hard for your child, let the school know that your child will need someone to accompany him or her to and from the bus or between classes. This person could be a teacher, school nurse, aide, or teacher’s assistant.

If your child is having difficulty holding a pencil or doing other daily tasks, you can ask the school to provide an occupational therapist who can work individually with your child on fine motor skills.

You will also want to make sure that the sinks and bathrooms are accessible to your child, and he or she can reach the faucets and use the toilets. This may mean asking the school to provide step stools in the bathrooms or getting a faucet that turns on automatically with sensors.

If I can be of further assistance to you please let me know. Good luck!

Leslie Granshaw
Granshaw5@aol.com
Lylaourlittlemiracle.blogspot.com
Mother to Lyla (16 month Achon) and Emma (4 year old AH)

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**Keep Your Information Updated!**

If you need to update your information with LPA, go to the main website, lpaonline.org and login. Then click on “Members Corner” and select “My Profile” to view and update your contact information. Or, you can email your updated information.
CREATING A CULTURE OF ACCEPTANCE ~ Keren Stronach
There has been a lot of discussion about social bullying and isolation in the media. However, there is no quick fix, and parents and schools often scramble to find ways to deal with scapegoating and bullying.

Fortunately, there are a growing number of organizations that are developing tools and resources to combat bullying and help children and teens develop a more positive attitude towards differences.

At the national level, Beyond Differences is a group that works in schools from the ground up to reduce isolation and to help kids see past differences. The Anti-Defamation League also provides an array of resources for schools to draw upon to create a more inclusive and accepting culture.

Schools are also independently developing their own curriculum. At The Berkeley School in Berkeley, CA, Kate Klaire explains that creating a culture of tolerance, respect, and kindness requires a pro-active approach that engages children and teachers throughout the school. Drawing in part on Susan Diamond’s book Social Rules for Kids, Kate regularly visits each classroom to work collaboratively with the teachers and the children to develop social rules for the class and the school in general. By doing so, she gives kids the agency, tools, and language to advocate for themselves and each other. This starts in Kindergarten, where the class discusses how to treat others and how to care for themselves and their community. Role playing is done to demonstrate how different interactions feel and how to say things in a way that another can hear it. The school also has a representative student council with kids from each class that helps to monitor interactions in the playground and design social rules for new situations that arise.

If you have suggestions or resources for effective ways to deal with bullying, please send them to keren@eaconsult.com.