

I Linå'la-ta OUR LIFE



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Administration on Intellectual Developmental Disabilities Tri-Agency



New Parent Advocacy Group Established By Dana Rohr



The board of the newly formed Parents Empowering Parents of children with Disabilities inc. (PEP inc.), includes (L-R): Ana Kilroy, Anna Catahay, Michelle Cruz, Leone Rohr, Carol Darlow, Arleen Goodson, and Pauline Camacho (not pictured).

2014 is just beginning, and with the New Year comes a group focused on helping and educating families who have children with disabilities.

Parents Empowering Parents of Children with Disabilities inc. or PEP inc., a parent organization, is on a mission to train, advocate, empower and support parents of children with disabilities.

"I believe there is a better way for people who have children with disabilities who need help," says Leone Rohr, one of the founders of PEP inc.

Parents Empowering Parents aims to build the spirit of teamwork with parents and the community of agencies on Guam to work together to improve educational outcomes and adult lives of individuals with disabilities.

"We believe in the power and necessity of having a vision for your child's future," Rohr says, "to work to set goals and to plan and execute action steps to reach these goals."

Rohr and a team of women have taken on the challenge to aide children with disabilities to live lives of dignity, to achieve their true potential, and excel in all areas of their life, academic and otherwise.

The Women Behind PEP inc.

Fellow founders Carol Darlow, Arlene Goodson, Anna Catahay, Pauline Camacho, Ana Kilroy, and Michelle Cruz, who joined Leone Rohr to create PEP inc., have a lot planned for the future.

"PEP has several training sessions/workshops planned for 2014 to include IEP, Goal-writing, Transition, IDEA Law, and Assistive Technology.

"We are also looking forward to planning an island-wide disability conference in May with keynote speaker Jo Mascarro, who is a consultant who provides training in areas such as behavior intervention practices, communication strategies, parenting skills, and programming for students with disabilities.

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New Parent Advocacy Group Established *...continued from cover.*

In addition, we are looking at planning some awareness and fund raising events," says parent and founder, Anna Catahay.

Catahay also shares some insight as to why she is so involved in this cause and why it is so important for parents to have the knowledge PEP inc. plans to provide.

"My daughter, Miana, is 3 years old and has Spina Bifida. She is unable to stand or walk, or use the rest room on her own. My husband and I do our best to do physical and occupational therapy with her. We have to understand everything from IEPs to goal writing to therapy techniques to catheterization to shunt malfunction. We have to compensate for the services or specialists that are not available to her on Guam.

"While other kids her age are running around and exploring, we do our best to keep her engaged as she is unable to run around and explore with them on her own. As she is getting older, she is realizing her want and need to interact with her peers and to be more independent, yet she is not fully able to...and we grieve. As her mom, I feel that it is up to me to do everything for her...I have to be "supermom".

"To this day I still feel this need, but I have to understand that she is growing up and growing more independent. I need to foster this independence and help her adapt so that she can be a participative member of society. Fostering this independence requires services and support from others and I have to be cognizant of the resources out there. It can be inundating at times. I have to realize that I can't always do "everything" on my own, but I do have to continue to advocate for her and educate myself so that she can live a productive life. That is why I am a part of PEP. They are my resource for Training, Advocacy and Support and we are happy to be that resource for other parents."

Catahay, like many parents out there, is making the best of the resources she has. Parents Empowering Parents inc. works to improve awareness, education, and opportunity for the community of parents who are going through similar experiences.

Carol Darlow, another mother and founder, also shares why she has chosen this role in the world of disabilities.

"I became interested in the formation of a non-profit



(L-R): Anna Catahay, one of PEP's Founders, is shown here with Miana, her daughter, and Jonathan, her husband.

organization whose main purpose is the empowerment of parents so they can effectively advocate for the needs of their child with disabilities.

"There was a need to found an organization that parents can be referred to for assistance in locating resources, training in the IEP process, and teaching parents how they can effectively advocate for their child. There have been other organizations that have offered limited and sporadic services. There is a need to establish a center to which parents can come for assistance and to which other agencies can refer parents who need support and training.

"There are many unmet needs of [people with disabilities] in our community and it is hoped that as the membership grows, we will be [a] voice heard by our government and business leaders. There is a need for access to housing, transportation, employment, better education, improved community supports such as mental health, medical care, and respite care for families to mention [a] few."

From one parent to another, Darlow adds, "As a parent, to hear that you have a child with severe disabilities that will persist throughout life is very difficult to bear. Every parent has dreams of their children living independently, holding jobs, having a family of their own, and experiencing the feelings of joy and accomplishment.

These dreams are dashed initially and it [is] as if the future has been taken from the child. Gradually we learn

to accept and move on to work at ensuring the child is able to achieve his/her potential. And we learn to rejoice with the most trivial gains that most parents take for granted.

We begin to think about how we can find a way to ensure the child is educated, prepared for some trade, occupation, profession or other activity after graduating from high school. We begin to find ways our children can succeed despite their disabilities, hope begins to grow and we reach out to help other parents remembering where we once were."

PEP inc. Plans for the Coming Years

Aside from educating parents with workshops, PEP inc. plans to build a Disability Parent Center from the ground up, and to add more to their umbrella of customers, such as:

- At-risk children
- Adults with disabilities
- Special Education
- Transition Services and Opportunities
- Training for Teachers
- Self-Advocacy Training

"This year PEP will sponsor IEP trainings, workshops in the areas of writing goals and post-secondary transition as well as meet with parents and others in the community to grow the organization. There are plans to have a conference and eventually to establish a center. Because these activities require financial resources, there will be fund raisers," says Darlow.

For now, as PEP finds their footing, this non-profit organization will be establishing itself in the field of parent trainings, disability awareness, offering support to parents, and empowering the parents to advocate for the specific needs of their child.

The Community Can Help Too

"The community can support our foundation by word of mouth...letting others know about us, especially parents of children with disabilities. The professional community and agencies can also support by collaborating with PEP on different levels in providing awareness, outreach, and services. Becoming a member of our organization provides network and financial support. Also, be on the look out for awareness and fund raising events where the community can also be involved



Leone Rohr, PEP inc. boardmember, proudly displays the "Incorporation Certificate" for the newly established non-profit organization.



(L-R): PEP inc. Board members, Pauline Camacho and Anna Catahay confer during a recent meeting.

in a variety of aspects from preparation to participation in the event itself, to donations," Catahay says.

To contact Parents Empowering Parents of Children with Disabilities inc. and find out more about their mission, or to learn about their next workshop, feel free to call Leone Rohr at 929-4157 or Carol Darlow at 727-2535 or send an email message to pepguam@gmail.com.



Comprehensive Age Planning for
Individuals with Disabilities and their Families:

Information Needed to Make Informed Decisions

Guest Faculty Presenter:
Katherine A. Campbell, J.D., LLM

LEGAL DISCLAIMER: Katherine Campbell is licensed to practice law in California. The information provided is not legal advice and does not create an attorney/client relationship. The information provided in this conversation is intended to provide general information about the topics covered. Individual situations and particular facts may make the general information provided unsuitable. Participants should contact their own attorneys for answers to their personal situations.

This presentation will focus on
integrating

- legal,
- medical,
- life and
- resource planning

to provide a better future for a person
with a disability.

Date and Time:

Wednesday, Feb. 26, 3:30-5:00PM

Location:

IT&E Lecture Hall,
Jesus & Eugenia Leon Guerrero School of
Business and Public Administration Building,
University of Guam

To Register:

Call 735-2477 or
email margie.johnson@guamcedders.org



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2014-2015 GDDC Executive Board



The members of the 2014-2015 Guam Developmental Disabilities Council (DDC) Executive Board pose with Council staff after their election. (L-R): Rosanne Ada, DDC Executive Director; Josephine Guerrero, First Vice Chairperson; Lisa Ogo, Secretary; Erlinda Tydingco, Chairperson; Lourdes Mendiola, Second Vice Chairperson; and Marie Tedtaotao-Libria, DDC Program Coordinator.

Transition to College: Breaking Down Barriers By Maria Bontogon



As part of her transition plan and in preparation for the start of her college career, Maria Bontogon (foreground), works on her orientation & mobility skills at the Humanities and Social Sciences Building on the University of Guam campus. Her teacher, Diane Artero (back), facilitated this lesson that took place on January 16.

Education tangibly shapes our brains and future, gives us the deepest passion which intersects with our greatest abilities, providing us an edge in the world of work and getting us to a higher standard.

These reasons persuade me more to go to college, although obviously there will be hurdles to surmount given my situation and condition. Thanks to those who created and passed significant laws governing education and which critically assist people with exceptional needs to triumph over challenges. Let nothing stop you from going to college—not even those doctors' prognosis

about whatever varied physical or chronic disabilities that fill-up your medical records, nor the lack of finances. Support agencies and federal scholarships, grants and loans are available.

College is a radical change from high school. IDEA 2004 and IEPs no longer apply. Instead, Section 504 of the Rehabilitation Act of 1973 and Americans with Disabilities Act (ADA) of 1990 guarantee the civil rights of people with special needs in the US, which mandate programs provide auxiliary aids and services. One necessary starting point is creating a "Transition Plan"—a coordinated set of activities designed for students with special needs that support improved academic and functional achievement to facilitate his/her movement to postsecondary goals. Contacting Department of Vocational Rehabilitation (DVR) may also help lessen some of the challenges, depending on eligibility. From the postsecondary school, the student and parent may inquire about academic requirements, financial aid, tuition fees, health/safety procedures and policies, technology resources, housing/food safety and other student resources/programs (counseling, mentoring, social and recreational opportunities, etc.). Students with special conditions who wish to request academic adjustments such as priority registration, course load assistance, issuing notetaker/device, extended testing time, etc., from the postsecondary school's accommodation office are generally required to submit verification of disability documentation from their health provider. Upon eligibility, reasonable accommodation/services may be provided based on individual needs.

Seeing and touching this impossible horizon is possible! How? Well... start off with passion and determination plus some meaningful support from parents, mentors and other advocates. To get in the door and play the game, do your homework-- ask, gather information, research and visit internet sites. I think a strong college path is achievable by learning to take risk, doing effective self-advocacy, gaining knowledge and understanding of civil rights laws, the college system and adult support services.

Maria Bontogon is a self advocate and currently a high school senior. She is excitedly looking forward to beginning her college career in the fall at the University of Guam.

Save the Dates!

GSAT Conference & Fair

Evolution of AT:

Celebrating the last 20 years and the next 20 to come!

March 1, 2014:

Guam System for Assistive Technology
Annual Assistive Technology Fair
Micronesia Mall Center Court

March 28, 2014:

Guam System for Assistive Technology
Annual Assistive Technology Conference
Westin Resort Guam

*For more information, or to request for reasonable accommodations,
contact: Guam System for Assistive Technology (GSAT)
Tel: 735-2490 | TTY: 735-2491 Email: gsat@guamcedders.org*



Autism Awareness Month Fair

Saturday, April 5, 2014

Agana Shopping Center

10am-2pm

*For more information, contact
Evelyn Claros at evelyn4families@gmail.com*

DISABILITY 101

A Tip from Lynn Tydingco

The "H" word!

It is offensive and politically incorrect to use the word "handicapped!"

Promote "people first language," such as "**Person** with a Disability."

More specifically:

A **Person** who is Blind

A **Person** who is Deaf

A **Person** with an Intellectual Disability

If you are a Person with a Disability,

EDUCATE DON'T HATE!

AT Corner: Introducing the NEW Prodigy Duo

By Carla Torres

Portability and simplicity are key factors in selecting assistive technology. With the new Prodigy Duo, one can get the best of both worlds. Humanware, a leader in assistive technology for people who are blind and have low vision, recently unveiled this product. The Prodigy is a personal vision assistant that is a magnifier and a reading system all in one. Being versatile, it allows the user to switch from a desktop magnifier to a hand-held portable one. As with many emerging technologies equipped with a touch screen, one can navigate the Prodigy by performing three gestures: tap, swipe, and pan. Long gone is the cumbersome X/Y table of yesteryear. Humanware also incorporated the Diamond Edge Text™ in its design which allows users to see sharp and crisp text no matter how high the level of magnification.

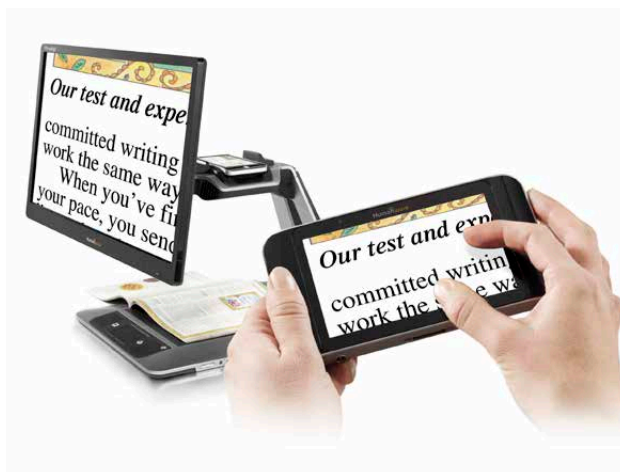


Image quality is never compromised, and images can be viewed in full color and enhanced contrast. Additionally, if one's eyes are fatigued or if one simply prefers to sit back and listen, the Prodigy allows for that, too. It has many reading modes and smooth flowing text that one can magnify, speed up, slow down or even go back, all without moving your page.

Humanware's new Prodigy™ personal vision assistant was granted the prestigious Silmo d'Or Award for Innovation and Creativity in Low Vision technology at the 20th award ceremonies at the Silmo 2013 Conference in Paris, France. The Silmo d'Or Ceremony awards the innovations that have been chosen and acclaimed by professions. (www.prweb.com/releases/2013/10/prweb11193334.htm)

The Prodigy Duo is now available for demonstration and loan at the Guam System for Assistive Technology (GSAT). If you are interested in trying this product or would like more information,

contact GSAT at 735-2490/1 or send email to gsat@guamcedders.org.



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Alternative formats (e.g., Braille, large print, audio tapes, or electronic file) of **I Linå'lå-ta** will be made available upon request. Please contact Margaret Johnson at 735-2477 (v) or 734-6531 (TTY), or email: margie.johnson@guamcedders.org for more information.



PARENTS EMPOWERING PARENTS
of Children with Disabilities, Inc.
Providing Training, Advocacy, and Support

GOAL WRITING WORKSHOP

Date: January 30 & February 6, 2014

Time: 6:00 pm-8:00pm

Place: PEP Office, ITC Building 1st Floor

Is your child receiving special education services in elementary, middle, or high school and does he/she have an Individualized Education Plan (IEP)? If so, this 2-hour workshop is for you. Your child's IEP should be a detailed plan that includes goals that will guide his/her educational team over the course of the next year. It is imperative that your IEP is appropriate to your child.

This workshop will:

- ❖ **Explain the importance of collecting useful data,**
- ❖ **Show samples of useful Present Levels of Academic Achievement and Functional Performance, and**
- ❖ **Explain SMART IEP's and provide examples of SMART goals and objectives.**

****Please bring your child's IEP to the workshop****

**** Space is limited to 6 participants per workshop, so please RSVP right away. Please let us know which day you would like to attend via email at pepguam@gmail.com or by contacting Leone Rohr or Carol Darlow.**

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