RST Family Fair

RST students in Saipan put on a glorious fair for the children and families who have been participating in the RST training program in 2004, and for our friends who have participated in previous years or in other ways. The fair was held at the Civic Center basketball court on Saturday, August 14. It was a partially rainy day, but cleared up by the end of the day. Over 100 people participated including children, family members,

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Looking Back- RSA Mentorship

The RSA Mentorship Program has been completed for 2003-4. Two site visits were made to each FSM state by the RSA Mentorship team between August, 2003 and March, 2004. During those visits we consulted around 81 children from the four states with written reports and recommendations. We held seven televideo sessions where we consulted around 13 different children, some live, and some through a case presentation by the RSAs. We did training on the following topics:

Making Toys from Trash, Inclusive Games, Promoting Mobility Skills, Hearing and Speech, Positive Behavior Support, Caring for the Child with Special Needs at Home

We also held an RSA Summer Institute in Pohnpei in June, 2003 with a focus on autism and early intervention, and an RSA Winter Institute in March, 2004 with a focus on the Functional Inventory of Pacific Skills (FIPS). Forty-five people attended the summer institute in Pohnpei, and 13 attended the Winter Institute in Honolulu. Fifteen people at the Summer Institute got credit through COM for their work that summer.

Other activities included supporting e-mail accounts for RSAs in Kosrae and Pohnpei, developing the Functional Inventory of Pacific Skills, and developing three videos around children in Kosrae and Chuuk. The project staff also presented about the RSA program in Washington to OSEP in March, 2004, and at the Pacific Rim Conference in Honolulu in March, 2004. Seven “RSAs On The Move” newsletters were published during the project period.

The RSA newsletter will continue to be published to keep everyone informed of RSA happenings around the Pacific.
Looking Forward

Opportunities for RSA training continue to be available in 2005.

Palau RSA training- January – November, 2005 in Palau (there may be opportunities for veteran RSAs as part of this training, I will let you know)

Pacific Rim Conference on Disabilities, Honolulu-February 28 – March 1, 2005

Osteogenesis Imperfecta

Osteogenesis Imperfecta (OI) is a rare genetic disorder that is characterized by brittle bones. Collagen (a major protein in connective tissue-skin, bones and cartilage) formation is impaired which causes problems with all of the connective tissue, not just bones. Besides frequent fractures, an individual with OI may have blue colored sclera (the white part of the eye); bending, shortness, or fractures of the long bones; poor tooth development; brown or soft teeth; short stature, scoliosis or kyphoscoliosis; lax ligaments; triangular face; and thin skin. Other problems can include heat intolerance (need air conditioning), excessive sweating, and potential deafness due to fractures of the small bones in the middle ear. There are four types of OI as follows:

Types 2 and 3 are the most severe, and are inherited from both parents (both parents must carry the gene).

Types 1 and 4 are less severe, but the child can inherit the gene from either one of the parents (both parents do not need to carry the gene).

In children with more mild forms of OI, the disorder may not be identified until the child has had multiple fractures. Because of the fractures, the parents may be evaluated for child abuse prior to realizing that the child has a medical condition causing the fractures. Children with more severe forms may be born with multiple fractures, and may not survive infancy.

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related services mentors, administrators from PSS and NMC, and others. Prizes that were generously donated by local businesses were given away throughout the day in a raffle. We played games including water balloon toss, musical spots, and a dance contest. Delicious food was donated by local restaurants and others, and was enjoyed by all. Children and parents created art projects and crafts at the arts and crafts table.

The fair was a tremendous effort by the RST students, and, despite the rain, was a rousing success. Students were successful at creating an environment that was accessible to all participants. Tents were provided for those who needed protection from the weather, Port-O-Potties were provided for those who could not walk long distances to other available bathroom facilities, and games were adapted so that all could play, enjoy themselves, and WIN!

Congratulations to the RST students of 2004 for putting on a wonderful family fair.
**Intervention for a Child with OI**

It is best to keep the following in mind when working with a child who has OI:

- **Recognize fractures** (child crying; vacant stare; hypersensitivity to touch; decreased interactions; unwilling to move arm or leg; redness, swelling, heat and discoloration at the site; fever). Not all of these signs need to be present for a fracture to have occurred. Medical care should be given immediately. Do not blame anyone for the fractures, they can occur spontaneously and not be anyone’s fault.

- **Prevent fractures.** Be careful moving limbs, especially while changing diapers, dressing child, or carrying the child. Pad crib rails, support both arms and legs fully when carrying (don’t let a limb hang down). For fragile infants, carry them on a full sized bed pillow or a bean bag chair for a larger child. Roll the child to change diapers rather than lifting the child by the legs. Never lift a child by the arms- instead hold the whole body.

- **Promote normal sensory experiences.** Make sure to talk to the child, move and carry the child, touch the child, and let the child explore water, sand, and other textures and substances. Water play is an especially nice activity that is safe and fun.

- **Promote normal developmental motor skills.** Help the child get into different positions (prone, supine, sitting, standing). Help the child move between positions, and move him or herself around the environment. Allow the child to do things for him or herself as much as possible.

- **Promote normal cognitive development.** A child with OI does not usually have a cognitive impairment. Expect the child to follow rules, learn in school, and help around the house as much as possible. You may have to adapt activities to prevent injury, but you should have high expectations of the child.

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**Photo Gallery: The Fair**

*Above: Linus cooks hot dogs in the rain in preparation for the fair.*

*Below: Mark and his family enjoy the fair*

*Bottom: Fair participants make marmans and other crafts.*
**Question and Answer**

**Question:** What can I do for an infant who has a fixed thoracic kyphosis? The child’s spine is curved forward in all positions, and can’t be straightened. The child is seven months old, but is functioning more at a 2-3 month level. He is very weak and has a diagnosis of muscle weakness. He likely has a genetic syndrome of some sort that hasn’t been identified yet. Should I stretch the muscles? What kind of positioning is best?

**Answer:** Generally I like to use positioning and handling to do stretching with little ones. That means that in the process of helping him move from prone to sitting up, I might help him move through his full range of motion in his trunk, including rotation. Or in the process of helping him get some weight bearing through his arms, I might help him rotate to the side to put his hands down on the floor (and teach his parents to do the same). Another activity is facilitated rolling (with his arms up above his head to stretch the shoulders) while lifting up his body a little so that he gets a stretch through his trunk into extension and rotation.

Reaching is the best way to try to get active trunk extension. Even facilitated (hand over hand) reaching with some support at the trunk to get extension may be helpful.

Try putting him in prone with a roll under his chest, and help him prop on his elbows over the roll. He will likely need some help to hold his head up, but it will be a good opportunity for him to practice. That way you get passive trunk extension, and an opportunity to practice head control, plus some weight bearing through his elbows. If he won’t tolerate prone, you may want to try having him in sitting with anterior support to his chest, and getting him to look up at you, and to reach if possible.

He can also prop on his hands in that position to get some weight bearing.

The more you can do to get him moving (in any direction!), the more he will learn about where his body is in space, and will be motivated to move more himself. He will also gain strength to help him move.