Transition: It’s a family affair

by Gwendolyn Brown, parent

On July 2, my son, Erech, and Vickie Stovall, a peer advocate with Disability Rights and Resources, ventured out together to help Erech work on better developing some of his independent living skills. While this kind of activity just so happens to be one of Disability Rights and Resources’s core services, the peer’s time invested in listening to my son’s desires, goals, and accomplishments has done so much to benefit Erech. He continues to focus on transitioning into various communities, both with and without additional assistance.

Disability Rights and Resources strives to make its services for individuals with disabilities consumer-driven. One of Erech’s many goals is learning how to use public transportation to traverse downtown Birmingham and visit various area attractions, such as the Birmingham Museum of Art.

With the help of his peer advocate, my son is becoming more confident in exploring downtown Birmingham. He’s learning numerous pedestrian safety tips, such as reading and obeying street signs, and he is also learning hands-on about our rich Civil Rights history that is found at exhibits in Kelly Ingram Park and other sites.

My son’s peer advocate has also set aside time to work on developing his money management skills and has even taken him on a lunch outing, where he had an opportunity to put his money managing skills into action.

Erech is 16 years old and at the height of his transition phase. I consider this period of transition to be a family affair because it is with confidence and trust that I have stretched my apron string in connection with the organization that I work for as well. The pictures above speak volumes to me because I not only continue to see my son reach his goals, I am witnessing my own dreams for him become a reality.

With the help of Disability Rights and Resources and many other resources that are a part of his team, we are certain that he will continue to excel toward a meaningful, independent life within the years to come.

While it feels a bit odd to thank my workplace for its involvement in my son’s continued success, I really shouldn’t feel that way. After all, it is indeed a family affair!

Gwendolyn Brown works at the Alabaster office of Disability Rights and Resources. You may reach her by email at gwen.brown@drradvocates.org or by phone at 205-685-0570.
From the
Director’s Chair

Hello, Parents,

CRS leadership has seen many changes over the past few years. Those of you who have been a part of our program for a long time probably have already noticed. Here’s a list of current CRS district supervisors and office coordinators by district and office, along with their toll free numbers to assist you in staying in touch. You may contact them to discuss issues or concerns, or to just reflect on what CRS services have meant to you and your family!

— Melinda Davis, CRS Director

<table>
<thead>
<tr>
<th>District / Office</th>
<th>District Supervisor (DS) / Office Coordinator (OC)</th>
<th>Toll Free Number</th>
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<tbody>
<tr>
<td>Anniston CRS</td>
<td>Randy Whitt, DS</td>
<td>1-800-289-9533</td>
</tr>
<tr>
<td>Gadsden CRS</td>
<td>Emma Hereford, OC</td>
<td>1-800-289-1353</td>
</tr>
<tr>
<td>Dothan CRS</td>
<td>Candace Mitchell, DS</td>
<td>1-800-677-9123</td>
</tr>
<tr>
<td>Andalusia CRS</td>
<td>Brandi Thomasson, OC</td>
<td>1-800-723-8064</td>
</tr>
<tr>
<td>Homewood CRS</td>
<td>Randy Hebson, DS</td>
<td>1-888-430-7423</td>
</tr>
<tr>
<td>Birmingham CRS</td>
<td>Cassie Sigler-Allen, OC</td>
<td>1-800-285-9318</td>
</tr>
<tr>
<td>Huntsville CRS</td>
<td>Tammy Meyer, DS</td>
<td>1-800-283-9352</td>
</tr>
<tr>
<td>Muscle Shoals CRS</td>
<td>Kimberly Wright, OC</td>
<td>1-800-285-9924</td>
</tr>
<tr>
<td>Mobile CRS</td>
<td>Tonya Beech, DS</td>
<td>1-800-879-8163</td>
</tr>
<tr>
<td>Jackson CRS</td>
<td>Jennifer Overstreet, OC</td>
<td>1-800-283-8140</td>
</tr>
<tr>
<td>Montgomery CRS</td>
<td>Kimberly Waugh, DS</td>
<td>1-800-568-9034</td>
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<tr>
<td>Opelika CRS</td>
<td>Kimberly Waugh, DS</td>
<td>1-800-568-8428</td>
</tr>
<tr>
<td>Tuscaloosa CRS</td>
<td>Barbara Hankins, DS</td>
<td>1-800-723-0490</td>
</tr>
<tr>
<td>Selma CRS</td>
<td>Melvina Moss, OC</td>
<td>1-800-967-6876</td>
</tr>
</tbody>
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This material is available in alternate formats upon request. Alternate formats include braille, large print or audio tape and may be obtained by calling the phone numbers listed above.

In the provision of services and employment practices, the Alabama Department of Rehabilitation Services does not discriminate on the basis of sex, creed, national origin, religion, race, age or disability.
An accessible garden

by Rachel Sepe, parent

Reprinted with permission from Complex Child E-Magazine

When the weather is warm, I am always on the lookout for fun ways to get my children outside to enjoy nature. It can be challenging, though, for children in wheelchairs to really get in touch with the great outdoors. It seems the equipment always comes between really touching and exploring grass, dirt, and all of the many wonders that are found right in your own backyard.

When our spring flowers began to bloom, my youngest was curious about how plants grew and asked to garden. However, she is too weak to really dig and plant in the yard, and her power wheelchair makes it a challenge to get up close to our landscape. With the help of neighbors, we took an idea from Pinterest and created Scarlett’s garden, which brought nature within her reach.

By measuring the span of her chair, we decided on a six-foot-long, U-shaped table moveable around our yard and patio. A trip to Home Depot allowed Scarlett to select vegetables, herbs, and flowers she wanted to grow, and the purchase of a toy watering can meant she could take care of her baby plants on her own.

Scarlett now checks on her garden daily and has many plants successfully growing. We can’t wait to eat her veggies later this summer, and are already enjoying many of the herbs. An accessible garden could easily be made larger or smaller depending upon your space, and even container gardens would give a child a sense of pride and connection to nature.

Rachel Sepe is the mother of three children and lives in the Chicago suburbs. Her youngest daughter, Scarlett, has spinal muscular atrophy. Scarlett’s journey can be followed at www.wishesforscarlett.com or at www.facebook.com/pages/Wishes-for-Scarlett/182231591882337.

Pimp your aids!

by Melissa Watson, parent consultant

My daughter, Olivia Jane, was fitted with her first pair of hearing aids when she was three months old. She has always worn pink hearing aids with glittery molds – we just always had fun with them. My thinking was that if my daughter has to wear them all day every day we might as well let her express a sense of style and glam them up!

At first, I dazzled her aids myself with rhinestones and stickers. The art projects were fun, but I recently came across a website that would pre-dazzle them for me: Tubetastic Pimps. I know, I know! Their name is certainly silly, but they do have some of the coolest accessories to personalize virtually any behind-the-ear (BTE) hearing instrument or cochlear implant that I’ve ever seen.

Tubetastic Pimps are easy to install and no special tools are required.

Simply remove the standard tube from the hearing aid or cochlear implant and slip the pimped charm through the tube on the back of the charm. Snap the new tube on to the hearing aid or implant and you’re off!

Tubetastic Pimps has its own Etsy shop online (www.etsy.com/uk/shop/TubetasticPimp), where you can choose from a variety of fun styles for girls or boys.

You will receive one Tubetastic Pimp, so it is easy to mix and match. Besides, if you only have one hearing aid or cochlear implant, it is pointless to buy a pair.

To date, I have ordered too many pimps to count from the Etsy shop and have never had a complaint about any order. Each charm is so cute, and we now can practically accessorize Olivia’s hearing aids to match her outfits!
CRS offices clean up at wheelchair washes

by Ryan Godfrey

This August, CRS offices on opposite ends of the state held wheelchair washes for children with special health care needs.

In north Alabama, the Muscle Shoals CRS office held its first-ever wheelchair wash and carnival at Spring Park in Tuscumbia.

Coordinated by Muscle Shoals CRS staff, the event attracted 300 local children and adults, with 40 volunteers pitching in to wash 25 wheelchairs.

The free event included train rides, carousel rides and games, misting rocks, bubbles, fire trucks, police cars, pizza, and snacks.

Some 10 community agencies and vendors were on hand to explain their products and services. The event also received extensive coverage in the local media.

On the southern end of the state, the CRS office in Mobile washed 20 wheelchairs at its event.

Children and families from the area enjoyed creating various arts and crafts projects in addition to the face painting.

Parents attending the wash were treated to free massages.

Lunch was generously provided by Olive Garden, with Publix donating cookies and cakes for dessert, and Numotion stopping by with doughnuts for breakfast.
Even more cool stuff!

Handy gadgets and the lastest tech to help parents of children with special needs

by Melissa Watson, parent consultant

I was doing a bit of research on new technology for children with special needs and came across two new innovations that have come out recently to help families of children with special needs.

The first is an app to help the blind “see” with their ears, and the second is a harness that makes it possible for children in wheelchairs to take a walk with their parents.

EyeMusic SSD (for sensory substitution device) is a smartphone app developed by researchers at the Hebrew University in Jerusalem that allows people with vision impairments to perceive color and shape through music. The app uses a computer algorithm to create sounds that convey visual information through sound. The music is then interpreted by the user to “see” what he or she hears. The system obviously isn’t perfect, but is helpful to someone needing additional information on colors, shapes, or locations from the world around.

For instance, when someone is smiling, a visually impaired person would hear a string of high notes quickly descend and ascend again to create a visual image of a U-shaped curve, like a smile. A frown would create the opposite – low tones that ascend and abruptly descend.

The app is not perfect and is still very much in development, but if you are curious, it is available for Apple devices. (free from iTunes)

The vOICe is a similar app that is available for Android devices. (free from Google Play)

As a parent, there can be nothing worse than hearing that there is something “not right” with your child. The idea for the Firefly Upsee harness was born when parent Debby Elnatan was told that her child would spend his entire life in a wheelchair.

Because she refused to accept that she could never go for a walk with her son, she spent several years developing a unique harness system that allows a child to take steps in unison with his or her mom or dad. With Elnatan’s invention, children with mobility limitations are able to enjoy this simple activity that millions take for granted every day.

Though the harness is on the expensive side ($499), in my opinion, this purchase has to be among the most rewarding that a parent could possibly make for his or her child. To take a walk with your child for the first time is priceless.

Harnesses are available for ages 1 to 8, with the largest harness safely accommodating a maximum weight of 55 pounds.

For more information or to order, visit www.fireflyfriends.com/upsee

Parents, do you have any additional tips or useful items to share? If so, let us know about it by posting them to our Facebook page, www.facebook.com/crs.parentconnection.
‘Show Me the Rule!’
An effective way to overcome special education problems

by Susan Agrawal
Reprinted with permission from Complex Child E-Magazine

During the many years I advocated for my daughter to receive her free and appropriate public education, I repeatedly heard denial statements like the following:

- We don’t provide that service
- That isn’t available
- You must do this before we can do that
- That is too expensive
- We’ve never done that before
- This is always how we do it; we can’t do it that way

These sorts of denials, which I like to call “soft denials,” are one of those rare cases when NO doesn’t really mean NO. In this case, NO means, “We won’t do this unless you make us do it.”

There is one easy and effective way to give a nudge to the school to help get what you need: using a technique I like to call “Show Me the Rule!”

What is ‘Show Me the Rule!’?

“Show Me the Rule” is an effective technique that can be used by parents to convince a school administrator or IEP team member to reverse a denial without needing to become confrontational or belligerent. Whenever you encounter a soft denial like those listed above, simply ask — as innocently as possible — to be provided with a copy of the rule in writing.

The way you ask the question is of critical importance. It must be done with innocence and kindness, such as in these approaches:

- I’m not that familiar with special education law. Would you mind showing me where in the Individuals with Disabilities Education Act that rule is?
- Could I please have a written copy of your policy that does not allow nurses in the classroom so I can find an alternate solution?
- I’m not sure I understand the process of obtaining an augmentative communication device. Could you give me a written copy of the policy that shows what benchmarks my child must achieve before she is eligible for a device?
- Can I have a copy of the state policy that limits occupational therapy to once a week?

You would be surprised that more often than not, no written policy exists. Instead, you might get a lot of hemming and hawing that this is just how things are done. At this point, it is critical to persevere, stating that you are more than happy to follow any guidelines that are written into federal or state law, as well as official district policies, but that if one does not exist, you don’t see why things can’t be done differently.

If the school does say there is a written law or policy but cannot produce it (or says they will get it to you in the future), give them the benefit of the doubt. Follow up with an email or written letter requesting the rule, law, or policy again, along with a follow-up meeting to discuss the issue further.

When is ‘Show Me the Rule!’ effective?

You cannot use “Show Me the Rule!” all the time. It only works when the school draws an arbitrary line in the sand that is not based in law or district policy. Often, schools do things a certain way because that is what they are used to. Unwritten policy may also be based on what is less expensive or even what the school thinks it can get away with unless challenged.

Overusing “Show Me the Rule!” can also be a problem. It should be used rarely and wisely and only for important issues.

When a rule does not exist, you have the opportunity to create an alternative to the way things are done. However, you must be prepared to have an alternate plan and justify why it is appropriate and necessary for your child.

Come from a place of cooperation

In general, techniques like “Show Me the Rule!” work best when they are asked in a spirit of cooperation. Remember, the IEP team and school district usually aren’t out to get you. If you treat them with respect, but also remember to be kindly assertive and cooperative, you are likely to achieve a better outcome.
Children’s Rehabilitation Service presented its five-year needs assessment survey results at the annual block grant review held Aug. 14 at the Alabama Department of Public Health (ADPH).

The needs assessment is conducted every five years by agencies that receive money through the Title V Maternal and Child Health Block Grant. The survey helps state maternal and child health programs determine strengths, weaknesses, and priorities.

In Alabama, funding for the federal block grant is received by ADPH. ADPH uses the majority of the dollars to support maternal and child health initiatives in the state, while directing a portion of the funds to CRS, which administers the state’s program for children and youth with special health care needs (CYSHCN).

Every state undergoes an annual review of its block grant application, with this year’s review also including a report on the findings of the needs assessment. ADPH and CRS officials typically travel to Atlanta to meet with reviewers, but this year was unique in that the federal reviewers agreed to come to Montgomery.

“Having the review in our home state is a real treat,” said Lolita McLean, CRS Maternal and Child Health coordinator. “It is something that we’ve asked for repeatedly, and this year we are delighted to have had the federal review team visit us here.”

Following the review, Project Officer Morrissa Rice, Deborah Brower, and Lorine Jay with the U.S. Department of Health and Human Services-Maternal and Child Health Bureau were given a tour of the Montgomery CRS clinic space by CRS Nurse Lisa Bachant.

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“This year’s review went really well,” McLean said. “A lot of positive changes have resulted from data received from previous needs assessment surveys, like identifying the need for a parent consultant in each CRS office, a transition social worker specialist, and a statewide youth consultant. Our many improvements show in our report, and we are proud to have these federal employees visit us to see our many programs in action.”

A WARRIOR’S SPIRIT

Children attending a recent Homewood CRS Limb Deficiency Clinics had the opportunity to visit with a soldier who lost a limb as a result of a service-related injury.

The visits are a part of a pilot program of the Army Wounded Warrior Program (AW2) and is being facilitated by Capt. Christopher Tanner, executive officer for the Army ROTC at the University of Alabama at Birmingham, and Delvin Maston, a retired staff sergeant in the U.S. Army.

Gara Johnson, CRS nurse coordinator, said the children as well as their families enjoy spending time with the soldiers.

“It’s really good for the kids to see adults with limb deficiencies who are living rich, full lives,” she said. “The soldiers are always very upbeat, positive, and encouraging. Most of their conversations have been so involved that we’ve had to interrupt them just so the doctors could see the patients.”

Federal Maternal and Child Health Bureau employees tour the Montgomery CRS clinic following the block grant review
The bumps in the road

by Rylin Rodgers, Family Voices of Indiana

Looking back to my now-teenage children’s early childhood, my first thought was my “white limo” fantasy. When my son was hospitalized as an infant and the complexity of his condition was not yet clear, my husband and I saw another family leave the children’s hospital in a limousine. That family was celebrating a successful surgery, resolution of the child’s issues, and a return to life as normal. This would be their last hospitalization, and they were going home for good in style. We turned to each other and pledged to do the same when our turn came, which would surely be soon. We would get through this current crisis, and we would move on with the normal life we had planned for our son. But that limo ride never came for our family, and it never will. In fact, in many ways, we have instead been on a very different and unexpected road, with wide variance in vehicles and driving conditions.

What I have learned from this journey is immense. First, while raising children who have special health care needs is the road less traveled, we were not alone. The families before us forged a path. The families currently on the road with us are the most wonderful traveling companions: giving, resourceful and resilient. And after a while I started to notice the families who followed, and hoped we were smoothing some of the bumps on the road for them. And while some sections of our road are built by families alone, most of our journey has been supported by professional builders.

The providers who partner with individual families and those who are working on system-level road design both have a tremendous impact. Home visiting systems give families access to tricycles and training wheels with the support they need to travel their own paths. Primary care medical homes provide whole child medical care and the partnership each family needs to navigate its course. Subspecialty providers give the critical care for very complex needs when sudden breakdowns occur. Financing the raising of my children has been a part of the journey in a constant state of change. At the moment families have increased chances of being insured on the road, but too many still can’t meet minimum coverage standards. Care coordination pilots are building the network needed to turn on the GPS system for families. The pit crew that supports our journey is extensive and endlessly important: therapists, medical equipment suppliers, teachers, community partners, even political leaders. It takes them all!

In the beginning, I didn’t know what I would need to effectively parent Matthew and Laura. Frankly, I had little knowledge of the world of systems and supports that would be crucial to their success in growing and learning. What I know now is that the road system out there is not yet perfect – there are bumps, potholes, unpaved stretches, and detours – but it is there, and amazing folks are working every day to smooth the journey and to build new and better highways. Your individual connection to maternal and child health is part of where we are all going. I thank you for putting on the work vest, even in less than ideal conditions. I urge you to continue to be alert to the needs of the travelers, point out the shortcuts, move the barriers, and cheer the journey. Sometimes I still wish for the limo ride; more often, I am aware of what I would have missed and that my family was meant to be on this road.
Book Review

Shelley, the Hyperactive Turtle
written by Deborah Moss and illustrated by Carol Schwartz
by Linda Collins, parent consultant

Here’s a great children’s book about a young hyperactive turtle who is so wiggly and jumpy no one wants to be around him.

While at school, Shelley agitates his teacher and classmates. He’s constantly in and out of his desk, and he just can’t sit still or be quiet. At lunchtime, Shelley throws his food to get attention and make other kids laugh at him. He only realizes things are getting bad when no one wants to be near him at the pond, his favorite place to be.

Parents of the other kids label Shelley a troublemaker and try to keep their children from approaching him.

Soon, Shelley withdraws and resents himself.

Shelley’s mom then takes him to the doctor. After many tests, Shelley is diagnosed as being “hyperactive” and having a condition known as attention deficit hyperactivity disorder (ADHD).

The doctor explains ADHD to Shelley as being something that causes some boys and girls to have more difficulty in being quiet and keeping still than others. Shelley’s doctor also tells him that having ADHD makes it harder to pay attention and follow directions.

I won’t spoil the ending, but the book goes on to explain what happens to Shelley after he learns he has ADHD and the steps his family takes to help him overcome this disability.

When first published in 1989, Shelley, the Hyperactive Turtle was one of the very first children’s books to discuss ADHD. Ever since, it has been a favorite among children, families, teachers, and therapists who all seem to enjoy the antics of this impulsive, wiggly, and mischievous turtle.

The second edition of this modern classic and bestselling children’s book includes an updated storyline with more relevant information on ADHD than what was understood about it in 1989.

Please stop by your area Children’s Rehabilitation Service (CRS) Resource Center at the nearest CRS office to check out this book and others on a variety of subjects, including: special needs diagnoses, issues, stories, consultations, and insights.

I promise you, you won’t regret it!

New Selma CRS office set for opening in October

by Ryan Godfrey

A major renovation currently in the works at 720 Alabama Ave. in Selma is good news for ADRS consumers in west Alabama.

That is the address for the new Children’s Rehabilitation (CRS) and Vocational Rehabilitation (VRS) offices that serve children and adults with disabilities in Dallas and the surrounding counties. Though the construction project kicked off just a few short weeks ago, visible signs of progress on the new facility are numerous, both inside and out.

The 12,644 square-foot facility will include many modern amenities, said ADRS Rehabilitation Specialist Mark Vosel, who is responsible for the department’s facilities.

“The new space will be approximately 65 percent CRS and 35 VRS,” Vosel said. “The CRS clinic space will feature an audiology booth, a modern exam and interview room, and an excellent parent resource area. VR will have a new conference room in addition to the new office spaces, and the rear of the building will have a covered entrance to better assist consumers and staff who are in motorized chairs when the weather is less than ideal.”

The new office is scheduled to be move-in ready by October and will replace the current Selma ADRS office, which is shared with Easter Seals.
One of the highlights of working alongside CRS State Parent Consultant Susan Colburn is joining her at the Alabama Governor’s Youth Leadership Forum (YLF) each year.

This year, we held a training on health care transition and emergency preparedness.

Throughout the session, we spoke on the importance of youth and families working together in the health care transition process.

One key thing we discussed is the need to start early. It’s important for youth to know that the earlier you start taking ownership of your health, the easier it will be in the long run. It will also help build confidence when it’s all in your hands.

The youth at this year’s YLF were great about asking and even answering questions about things that could help guide them through their health care transition.

Another tool that Susan and I have with us at every YLF is the Care Notebook that is provided by Family Voices of Alabama.

Inside this binder is a transition checklist to help you track your progress in self-advocacy through the transition period. Things like making your own doctor’s appointments or carrying your own health insurance card are steps you can take now to help you become better at advocating for your own personal health care needs.

Susan was also able to speak to this year’s YLF delegates about the importance of emergency preparedness for youth with special needs and their families. She highlighted an emergency preparedness kit that is included within the Care Notebook.

Something that we never fail to mention whenever we speak on health care is the importance of ensuring you always maintain an updated list of your medications and medical supplies that you currently use or need access to. Lists such as these are always important because families, doctors, or medical professionals may be in need of easy access to your information in an emergency situation. It’s so much better to have this all written down before an emergency because it is so easy to forget in the moment.

It’s always a joy to share my experience and knowledge with youth because I want to help them avoid some of the pitfalls that I — and many others — experienced growing up.

My take away from all of this?

Remember that transition is a process, but the more you speak up, the more you are heard. Health care is important. But once that responsibility is in your hands, it’s truly your healthcare and you. You can do it — there’s no better time to start your journey than the present.

Keep persevering and aim high!

A popular art program that had been at the CRS office in Homewood since 2005 was in danger of ending when the grant that funded it ended in May.

Thanks to the generosity of a Birmingham-area artist and Homewood CRS staff, though, children waiting to see various medical specialists at the Hearing Clinic are drawing and painting again.

Teaching artist Mary Susan Lewis — known as “Miss Sue Sue” to CRS families — was asked to volunteer her time, with Homewood CRS office staff dipping into their own pockets to purchase art supplies.

“The art program is good for the kids and gives them a creative way to spend their down time at the clinic,” said CRS District Supervisor Randy Hebson.
RAINFOREST ROCK

How many colorful fish can you count? _______________________

FUN FACT!
Male cardinalfish will carry their babies, both hatched and unhatched, in their mouths for up to 21 days!
Check Out What’s Ahead …

Sept. 18, 2015
2015 Alabama Newborn Screening Conference
Description: Alabama is celebrating its 50th year of newborn screening. The focus for this year’s conference will be on the history and timeline of newborn screening in Alabama. Dr. Harvey Levy, who was awarded the Robert Guthrie Award in 1997 for his contributions to the field of newborn screening, will be the keynote speaker. The conference will be at the Prattville Marriott Conference Center. Registration is $30.
Information: Cindy Ashley, cindy.ashley@adph.state.al.gov

Oct. 9 2015
Spina Bifida Awareness Football Game
Description: Several community agencies will be present and children and families will be recognized at the spina bifida football game, held at Fairhope High School’s stadium.
Information: Heather Horne, heather.horne@rehab.alabama.gov

Oct. 19-21, 2015
31st Annual Early Intervention and Preschool Conference
Description: The Early Intervention and Preschool Conference is a two-and-a-half-day event designed to share information and develop skills for professionals and families who work with children with disabilities (ages birth to five). The conference will be at the Montgomery Renaissance Hotel and Spa. Registration is $80 for families, $165 for professionals.
Information: Jeri Jackson, jbh50@aol.com

Local PAC meetings: Check your local CRS office for dates and times of meetings in your area.