Inside

Superheroes 2
Donations, Grants, and Special Gifts 3
Addison: A Beautiful, Thriving Miracle 4-5
Shelly Taylor: Intern to Case Manager 6
Feedback about RISP 7
RISP Vital Statistics 8

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Superheroes

We all need a hero during difficult and challenging times, and having a child with special needs or about whom there are developmental or health concerns can be one of those times. These heroes come in many forms: parents and family members who guide their children’s services; supporters who give in so many ways of their resources and talents; therapists who share their expertise; and most of all the amazing children who are filled with courage and strength of will, beating the odds and astonishing the world with what they can accomplish.

During the past year, the Rural Infant Services Program (RISP) had the privilege of serving 358 wonderful babies and toddlers. All of these children have special gifts, as well as special needs. As RISP has expanded to meet the growing number of children in need of services, new staff members have joined the team and have added their own special skills to the services already in place. The following pages offer you an opportunity to meet some of these extraordinary children and learn about the services they receive.

As in years past, families have expressed appreciation for the following anonymous poem, which is at the heart of the beliefs that drive the Rural Infant Services Program:

Each child is like a butterfly in the wind.
Some fly higher than others,
But each one does the best it can.
Why compare it to the others?
Each one is different.
Each one is special.
Each one is beautiful.

About RISP

RISP is a program of the public, nonprofit Middle Peninsula-Northern Neck Community Services Board, where the vision is “creating possibilities … changing lives.” As part of the statewide Infant and Toddler Connection of Virginia, RISP works toward this vision for babies and toddlers up to three years of age in the ten counties of Essex, Gloucester, King & Queen, King William, Lancaster, Mathews, Middlesex, Northumberland, Richmond, and Westmoreland. RISP has been providing a wide range of successful developmental and therapeutic services since 1983.

Your tax-deductible financial contributions to RISP can help additional young children have a positive start during the early years, when the most lasting benefits can occur. Funding continues to be needed to help expand early intervention services to the increasing number of babies and toddlers with special needs who are being referred throughout the Middle Peninsula and Northern Neck. For additional information, please call 800.305.2229.
The funding that makes early intervention services possible in our community comes from a wide range of public and private sources, including the Middle Peninsula-Northern Neck Community Services Board, Part C of the Individuals with Disabilities Education Act, local tax dollars, reimbursement from private health insurance and Medicaid, family fees, and private contributions from many generous and caring individuals.

In addition, RISP received the following grants from community organizations, churches, and charitable foundations that funded services, supports, and materials that made a significant difference in meeting the needs of the children served by RISP in 2010-11:

- Anonymous
- Abingdon Episcopal Church, White Marsh
- Bay Quilters
- Elis Olsson Memorial Foundation
- Felicia and Joan’s Angel Fund
- Gloria M. and Paul D. Hare Early Intervention Fund (a fund of the Mathews Community Foundation)
- Gloucester Community Foundation
- Grace Episcopal Church, Kilmarnock
- Middlesex Kiwanis Club
- William F. and Catherine K. Owens Foundation
- St. Andrew’s Presbyterian Church, Kilmarnock
- The Samaritan Group, Inc., Gloucester
- J. Edwin Treakle Foundation
- United Way of Greater Williamsburg (Donor’s Choice)
- White Stone United Methodist Women
- Zoar Baptist Church Ladies Bible Study, Deltaville

Some gifts for the children in RISP make a significant difference in their daily routine. Bay Quilters provided “therapy quilts” for floor time with the families. The smile on Delante’s face shows clearly how much he enjoys the activities that help him develop.
Addison was born with her trachea and esophagus attached, which affected her ability to breathe, eat, and move. This rare genetic condition, VACTERL Association, affects one in 100,000 children in different ways and left her with no way to eat and an airway as thin as dental floss, preventing air flow. Her left lung is not developed or functional, and she has one pulmonary artery going to her only working lung. Addison’s vertebrae have many anomalies causing her to have torticollis, where her neck is at a tilt, causing issues with balance. She will develop scoliosis with age as a result of having a hemi vertebrae. In December 2010, she was diagnosed with mild hydrocephalus resulting in premature thelarche, which causes the body to develop prematurely. She endured kidney failure, pulmonary hypertension, and many “codes.”

My husband and I had no medical history or genetic predisposition to assume our children would have to fight so hard to live. We listened to the doctors’ recommendations, researched the best plan for our baby and, most of all—prayed that her life would turn into something far greater than we could imagine.

At home we were caring for a fragile newborn that we assumed was on the mend. She was discharged just in time for Christmas with a feeding tube and a major oral aversion. She had worked with physical, occupational, and speech therapy while admitted, yet she still had so far to come. At four months old, she began to turn blue frequently at home and did not gain weight. Doctors told us that she was now considered “failure to thrive,” being in the 0 percentile in all categories of development. In March 2009 she was hospitalized with bronchitis, which weakened her only good lung. She then needed oxygen 24-hours a day, and without it she would stop breathing. Having an infant on a nasal cannula for oxygen and a feeding tube was a difficult task. We had to be extra attentive and always make her our main focus to assure that she was alive.

That same month, we were introduced to the therapists from the Rural Infant Services Program, who were a godsend to our sweet Addison. We were unable to take her to a facility for therapy because of her high risk for respiratory infection. We had first-hand experience with her sensitivity to illness and were thrilled to hear that this program provided in-home services with an experienced and compassionate staff. Enrolling in RISP was one of the least stressful experiences I have had. Addison’s first session started with occupational therapist, Vickie Bishop. The first thing I noticed about Vickie was her enthusiasm and positive approach. She came to our home prepared with an array of ‘tools’ and approaches to try. If something didn’t work, she would find something that would! She spent months working on Addison’s oral aversion and gross motor skills. Prior to working with Vickie through RISP, Addison would not take any food or liquids by mouth. She would ONLY breastfeed and take foods via her NG tube. Within a few months, Addison was eating baby food by spoon and drinking water through a straw!

In January 2010, Addison became very ill with an unknown respiratory infection. What we assumed was an allergic reaction was far worse. On January 31st in 14 inches of snow, my husband and I plowed our way for two hours to the Children’s Hospital of the King’s Daughters (CHKD) in Norfolk, Virginia and Cincinnati Children’s Hospital in Ohio. The following is adapted from a presentation Brandi gave at a MPNN CSB legislative event.

Addison was a beautiful, thriving miracle.”

Addison’s Story

by Brandi Senters

Addison and therapy dog Ripley

Addison and Matthew
When we got to CHKD, we learned that she should have been in a coma or worse with her levels of CO$_2$, but no, she was sitting up and playing, drinking the juice boxes (because of the help she received from Vickie Bishop). Addison's only lung was failing. She stayed in the Pediatric Intensive Care Unit for two weeks while tests were performed to try to find the cause of her illness. Matthew and I had to make the biggest decision of our lives. Addison would remain on the same downward spiral if/when she recovered, and we went home on oxygen. We decided to trach our daughter, with the assistance of a ventilator, to strengthen her lung. A tracheostomy was performed on February 16th. Within one week, she was able to breathe room air for a few minutes at a time.

Addison was admitted to the Transitional Care Unit for three months, where I lived by her side, three to six months pregnant, never leaving her. It was a remarkable transformation in such a short period of time; we were more than thrilled. Her weight increased from 13 to 18 pounds in just two months, with the ability to take steps at 18 months of age! Betsy Donoghue, Addison's service coordinator from RISP, stayed in contact with me during the entire stay, providing me with resources for assistance and much needed prayers. Addison received therapy while admitted, and we were excited to get back home to continue services with RISP. What a transformation she had made. When we left the hospital, she was off the ventilator for six hours as a “normal” kiddo!

Upon coming home, Addison was introduced to Brenda Wiley, physical therapist with RISP. If I could sum up Brenda, it would be FUN! She came to our home with exciting games and the energy to wow Addison. Her smile made our little girl eager to participate and easy to enjoy. Addison had a weak body and because of her torticollis, she would fall often. Brenda instructed Addison as well as myself on exercises that were safe and fun for her. Brenda brought the necessary equipment to each session, and we were able to utilize the tools between visits in the comfort and safety of our own home. Addison's favorite part was learning to jump from the small balance beam. Brenda always participated 100% in the physical activities, making it fun and enticing for Addison to jump on in. Brenda was extremely cautious when it came to neck exercises to help Addison turn her neck, which was a big concern for us. I greatly appreciated her positive energy and gentle yet effective approach. Addison can now run through our home without falling! She was climbing the stairs at 30 months old and is now able to sit up from a lying down position.

Addison also began speech therapy with Libby Harding through RISP. We have to make sure we tell Addison when Libby is coming because she gets so excited she runs to the window to check to see if she is there yet. While Addison was in the hospital, the speech therapist and I worked on sign language with Addison, since she was unable to talk. Addison has speech apraxia, where her brain is unable to make the appropriate connections to speak. She could only say “mama” and “baba” at almost two years of age, and she is now moving her lips to form many sounds and can blow bubbles through her mouth. This is such a huge accomplishment for her, as she was unable to pass air through her mouth, only her trach. Libby had so much patience with our active toddler. She would modify her lesson to best fit Addison that day. She even prepared a fun workbook for Addison to practice “homework.” I think Addison knew that if she listened to Libby, then she could decorate the binder with her choice of stickers! Recently Addison had a session with Libby and her therapy dog, Ripley! It was jaw dropping to see Addison petting an animal that she had been scared to touch before. She successfully walked Ripley around our yard and is still talking about that day.

In August 2010, I gave birth to a baby boy who passed away shortly after birth. Rural Infant Services Program respected our time of grief, and all sincerely sent their condolences when we needed it the most. It was as if we not only gained therapists but also a family with Addison. Since we could not travel much outside the home with Addison, they came to us. It was so nice to watch Addison grow with a group of individuals who cared for her and for our family. It was essential for her to receive therapy, but I can honestly say that I would have been petrified to take her outside during the worst of seasons. The staff members were always organized, efficient, and effective in the care they provided Addison. I am sad to know that as Addison turns three years old, she ages out of RISP. But, she has graduated from the program with much gain. I am blessed to have had the opportunity to work with outstanding people for almost three years.

I am incredibly honored to have been given the chance to tell my daughter’s story. May many other children with special or different needs be able to thrive with the help of the Rural Infant Services Program, just like Addison.
Shelly Taylor from Northumberland County selected RISP as her internship site when she was in the Human Services degree program at Old Dominion University in the fall of 2009. Shelly quickly demonstrated her “people” skills to the RISP staff and showed her clear understanding of the needs of children and families. With her background in Head Start and administrative support, she became an invaluable part of the services at RISP. Following her internship, she was hired by RISP as a case manager and is now the program manager for service coordination, ensuring that families in RISP are receiving the supports and services that will help them achieve the goals on their child’s Individualized Family Service Plan or IFSP.

When asked what is the best part of her job, Shelly said that it is seeing families “make it happen” by doing what needed to be done and connecting with the resources. When asked what is the most challenging part of her position, she said that it is frustrating when the resources that are so much needed in our area are not available, such as housing. And, as families have also shared, she says that it is sometimes bittersweet to say goodbye when the families leave RISP to graduate into one of the preschool programs.

Shelly’s work with families and her help ensuring that children receive comprehensive early intervention services were identified by RISP staff as one of the best service and program additions that made the most difference for success in 2011.

Did You Know?

Early intervention services at RISP for children with special needs from birth to three years old are required to be provided in the child’s “natural environment,” which is typically the home or day care setting.

During 2010-11, the 15 RISP therapists traveled more than 135,000 miles across the ten counties of the Middle Peninsula and Northern Neck to deliver these services to children. This distance is comparable to circling the earth almost 5½ times.

Families have told us that they very much appreciate receiving the services in familiar surroundings without having to travel and that this contributes greatly to their children’s success and developmental gains.
Feedback

From Parents

• [Our daughter] is a regular chatterbox now. She sings a lot, and it’s usually songs of her own creation! Thank you again for all the help you gave our little girl. We are so grateful that we had [staff member] as her speech therapist.

• I thought it was great! They got on the floor with my son and interacted with him. Everything was understood.

• I loved the experience [of assessment]; I feel that the program will be great for my child.

• This program is excellent…very professional and kind to my child.

• I really got the feeling that your team cared for my baby – thank you for caring. You were so helpful. Thank you!

• What would have made it easier to get these services? If I had known about it sooner.

From Students

RISP continues to serve as a practicum site for undergraduate and graduate students in Virginia universities, which this year included Old Dominion University and Virginia Commonwealth University in the areas of Nursing, Early Childhood Special Education, and Human Services. Comment from one student:

“I would like to thank you for such a wonderful practicum experience. It was such an eye-opening learning experience for me – that has truly made me a better teacher. Everyone … was so welcoming and kind and exceptional professionals. The staff is amazing. The families and children are beyond blessed to have you in their lives. You all make such a difference. Thank you for showing me where my children begin and how essential their families are to their success. Thank you for sharing your knowledge and experience with me – I will always be grateful.”
(MH, preschool teacher)

From RISP Staff

“Greatest strength: Everyone working together and supporting one another—continuing to be a great supportive team for each other; our awesome staff.”

“Best team in the world!”

“Lots of support, wonderful staff, great families and children.”

From the Commonwealth of Virginia

“Your continued increase in the number of children being referred and served under Part C is a testament to the quality of services that you provide. You truly care about the children and families and that is recognized by those in your surrounding communities. Thank you for your dedication to serving the infants and toddlers with delays and disabilities in the Middle Peninsula-Northern Neck area. You truly are making a difference.”

The Rural Infant Services Program:

- Exceeded the state target on how many families “strongly agree” that their services have helped the family “help their children learn and develop”

- Exceeded required number of children served in both the birth to 12 months of age and birth to 3 years of age categories

- Showed more than a 20% increase in the annual number of children enrolled on 12/1/10
RISP Statistics

Total Children Served in 2010-2011, by County (358):

- Essex: 44
- Gloucester: 88
- King & Queen: 11
- King William: 39
- Lancaster: 31
- Mathews: 22
- Middlesex: 24
- Northumberland: 38
- Richmond: 26
- Westmoreland: 35

Gender: Male 230, Female 128

Race:
- White: 215
- Black: 90
- Other: 27
- Hispanic: 23
- Native American: 2
- Asian: 1

Gender:
- Male: 230
- Female: 128

Insurance Coverage of Children Enrolled in 2010-2011

- Medicaid/FAMIS (including HMO): 182
- Private insurance: 65
- Tricare: 21
- None: 7
- Private insurance and Medicaid: 4

In addition to our thanks to all the generous donors of funds and materials, the RISP staff and families are also extremely grateful to Mary Grafton Yagel and Cullen Walker for their beautiful photographs at RISP events and to Helen Worthington for her assistance with the design and editing of our annual program report.

Children enrolled for full developmental services (Part C): 279
Additional children screened/monitored: 79

Services When Children Leave RISP:

In 2010-2011, RISP received 212 new referrals of children, from the following sources:

- Physicians: 96
- Parents/guardians: 64
- Parent-child programs: 17
- Department of Social Services: 12
- Hospitals: 12
- Infant-Toddler Connection: 3
- WIC: 2
- Day Care: 2
- Shelters: 2
- School: 1
- Insurance: 1

Diagnoses/Conditions of children enrolled for full services
(some children are in more than one category):

- Developmental delay: 182
- Speech delay: 62
- Motor impairment (includes torticollis): 43
- Prematurity: 38
- (extreme prematurity – less than 28 weeks): 25
- Medically fragile/health impairment: 23
- Other genetic disorders: 20
- Communication disorder (includes autism): 20
- Feeding disorder: 16
- Sensory integration disorder: 12
- Vision impairment: 9
- Down syndrome: 6
- Cleft palate: 4
- Accident: 3
- Hearing impairment: 3

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A Note of Thanks

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