

The Survivor, The Hero & The Angel

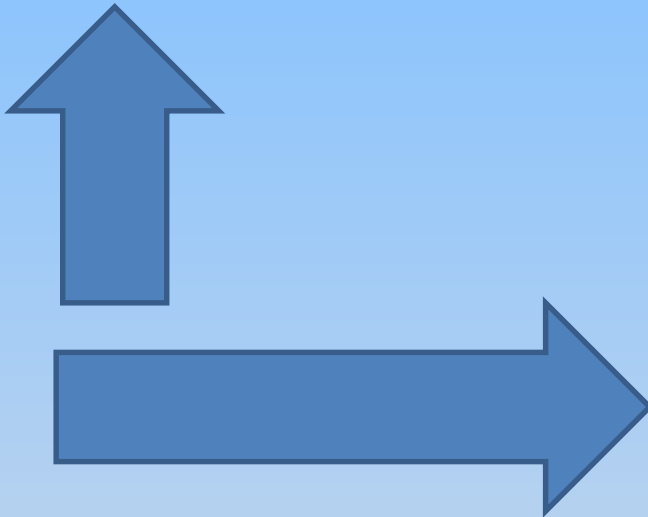
A Mother's Story – One Decade

By MaryAnn Raccosta

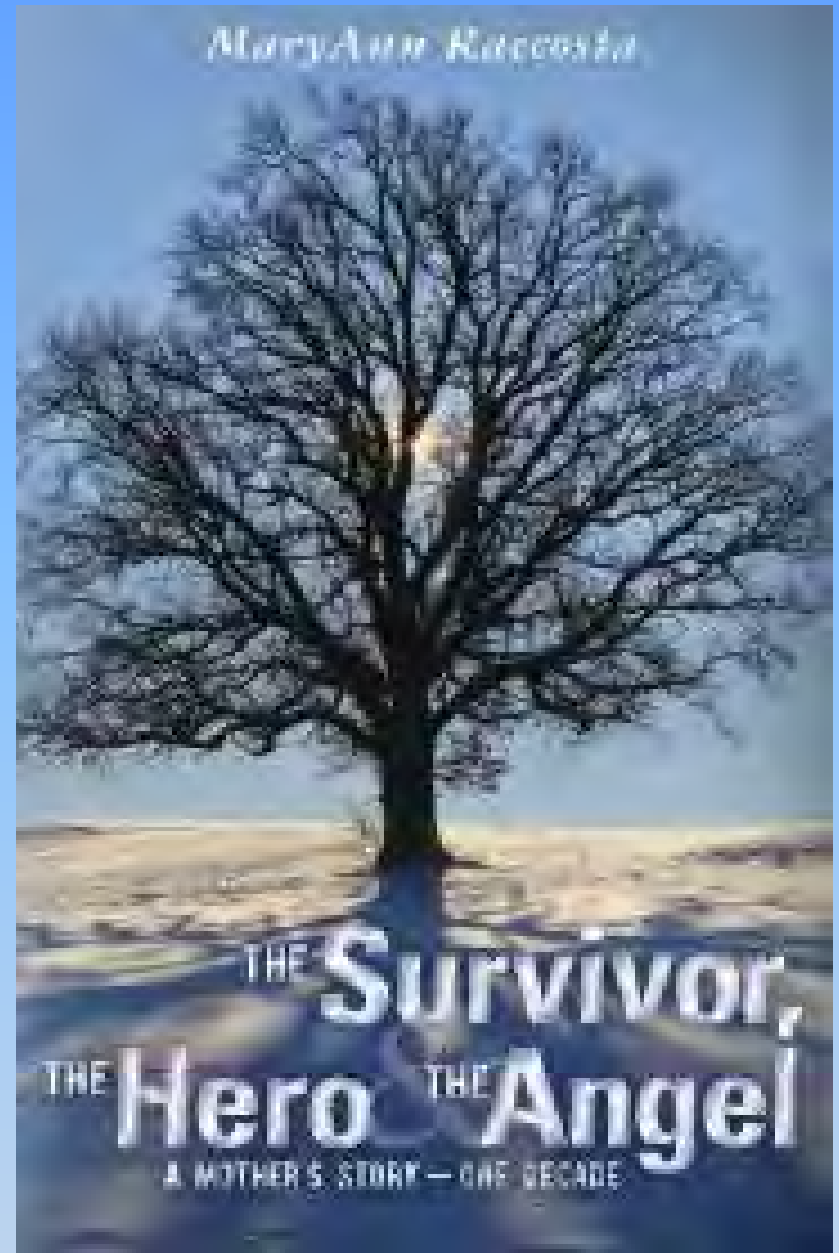
Thank you for existing!

Thank you for allowing
me to share my story.





Here we are!



James

- The story began in 1999
- “Thank God James had Liver Disease”
– without it –

we would never have known
about the extremely rare
metabolic disorder.

Sweet Baby James



**James was 6th case in the world of TFP.
“Like winning the lottery & being struck by lightning
on the same day!”**

Our life did not stop...



Sam was born, also with TFP!
Gabrielle missed Mommy.
Dad needed to work. Bills piled up!
Searched for "Normal."

**“We must focus on what lies before our
own eyes” - Mother Teresa**



Hospitalizations & Chaos

- In 2001 Cardiac Arrest!
- Exhaustion
- Desperation
- Chaos



What is the point?

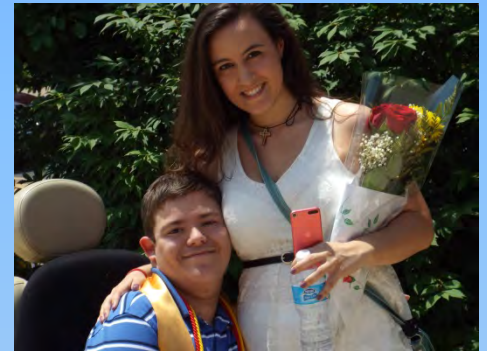


**“Life is a matter of interpretation. Perception
and Perspective are key.”**

- Maryann Raccosta

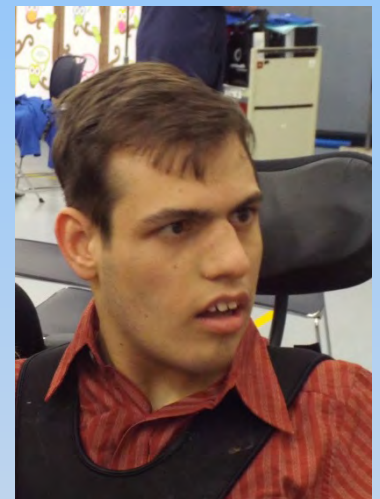
What do our stories teach us?

- Advocate for our children
 - Needs, Therapy, Education, Recreation
- Survive!
 - Exercise, bake, sleep, read
- Grieve, but regroup
 - Talk with others, staff, friends,
- Be Assertive, not aggressive
- Document important info – and feelings
 - Research sites; Find groups
- Remember your other children!
- Do not blame your spouse



Billow with the Wind...

- Billow with the wind has become my trademark
- Find courage - and new purpose
- Get involved – Volunteer & make a difference
- Have hope for contentment
- Deepen your Faith - Help others - Pray
- Remember you are not alone
- Continue to navigate your life



Experiences...





whether joyous...





Or filled with sorrow ...



are a tremendous gift...



And have given me much insight...



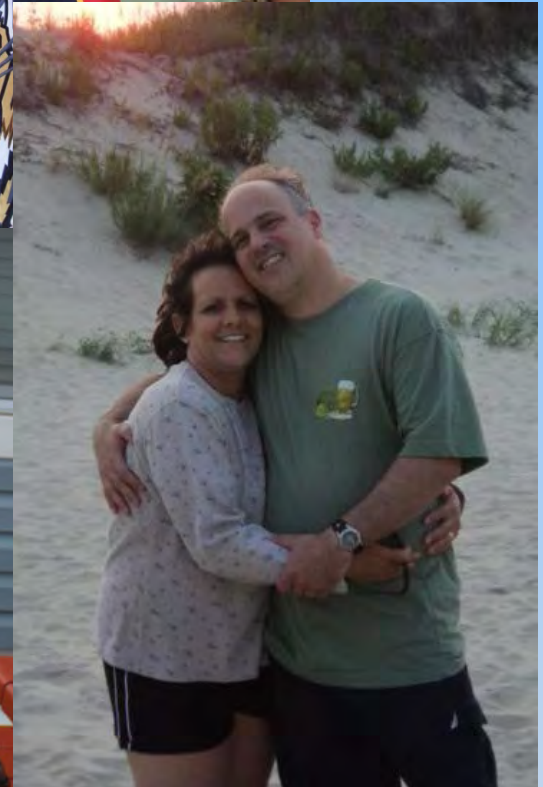
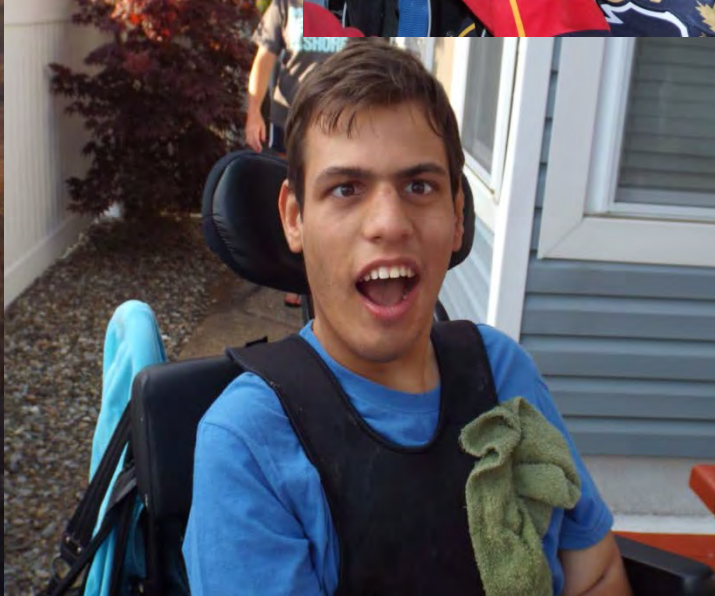


To the world,

That lives within



My mind...



My heart...



and my soul...



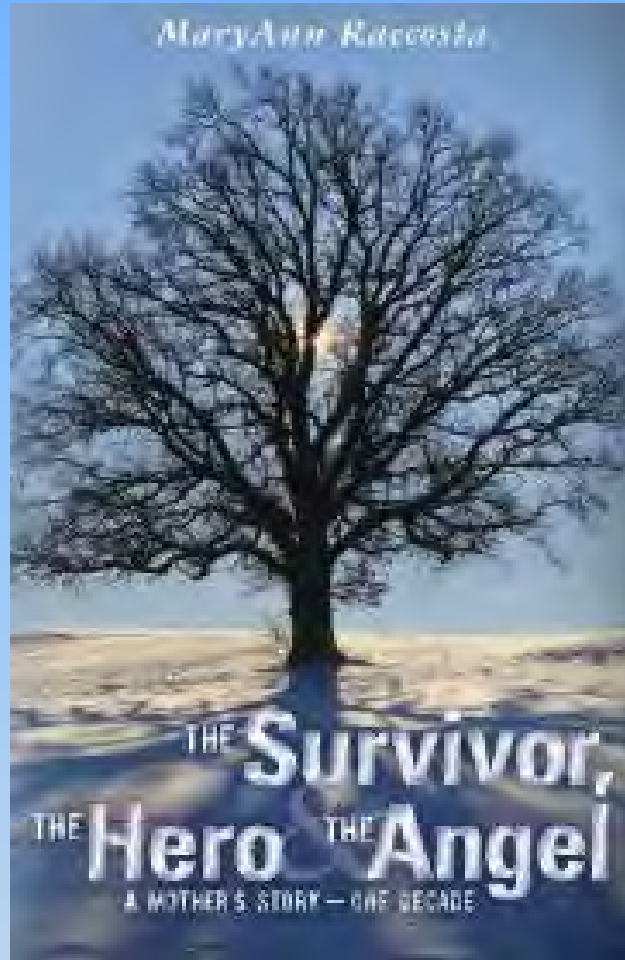
Just like the wind, time passes



without us really noticing...



Unless of course we stop
to feel it, sense it,





Billow with the wind.

Upcoming Webinar

Shriners Hospital for Children

About the program: We are recruiting caregivers of youth with spinal cord injury, ages 7-17, to participate in a study.

Caring for Caregivers:

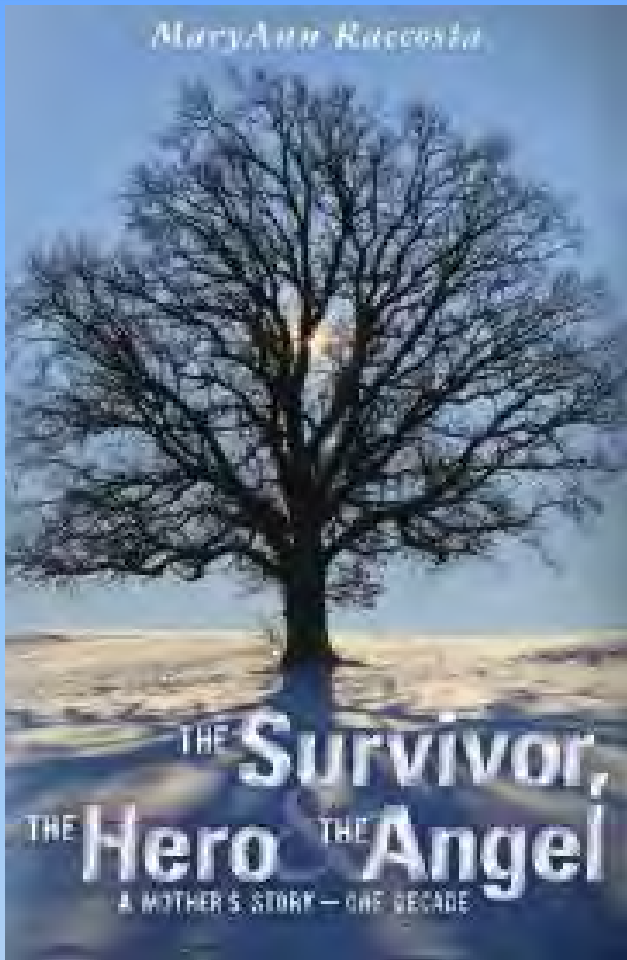
Supporting Caregivers of Youth with Spinal Cord Injury (SCI).

The biggest component of this study is a weekend program (“Parent Forum”) for the primary caregivers of children with spinal cord injuries (SCI). The Parent Forum is a 2-day in-person educational and support experience aimed at promoting caregiver problem solving and emotional health with the ultimate goal of improving quality of life for caregivers and their children. We have developed this program directly from feedback from caregivers of youth with SCI.

FOR FURTHER INFORMATION, CONTACT:

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