

# Hudson Valley Connections

## Parent to Parent of New York State

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### Contacts:

Parent-to-Parent NYS  
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### PTPNYS Hudson Valley

Regional Coordinator:  
Laura Carfi  
Parent Coordinator:  
Marina McGovern

### Our Websites

[www.parenttoparentnys.org](http://www.parenttoparentnys.org)  
[www.wihd.org](http://www.wihd.org)

### HELPFUL WEBSITES:

[www.wrightslaw.com](http://www.wrightslaw.com)  
[www.esopuscamps.com](http://www.esopuscamps.com)  
[www.parentknow.com](http://www.parentknow.com)  
[www.onthesameteam.org](http://www.onthesameteam.org)  
[www.hvparent.com/directories](http://www.hvparent.com/directories)  
[www.mysummercamps.com](http://www.mysummercamps.com)  
[www.npnd.org](http://www.npnd.org)  
[www.fathersnetwork.org](http://www.fathersnetwork.org)



### From The Coordinators: *Marina McGovern and Laura Carfi*

There are some new and exciting changes with our Parent to Parent NYS program in the Hudson Valley Region. The Wassaic office has merged with our Westchester office at WIHD. We are located in Cedarwood Hall, Room 335 on the 3<sup>rd</sup> floor. Eventually our office will be located on the first floor in room A106. The move will allow us to collaborate with other programs at WIHD that are valuable resources for families with children who have disabilities and special health care needs. You will be able to walk in and meet with us at your convenience. You will also find information, resources, and a lending library. We are always available by phone to provide a match and information or referrals.

We are part of the WIHD Links Network which is a collaboration of different programs designed to help individuals, families, professionals, and consumers to increase access to services and link individuals and families to the assistance they are looking for.

### Links Network Programs:

Emergency Preparedness  
Family Faculty and Advocacy  
My Health My Choice My Responsibility  
Parent to Parent NYS Hudson Valley  
Self Determination/Individualized Supports  
Early Childhood Direction Center  
Special Education Parent Center

### Seeking Families to Contribute to Our Newsletter:

We would like to include in our newsletter personal stories from families about experiences that they have had with their child with a disability or special health care needs. If you are interested in contributing poems, stories, or personal testimonies to our parent-to-parent newsletter, please contact a parent coordinator to discuss your ideas and submit your writing for possible publication in one of our issues. Book reviews can also be submitted. We look forward to sharing your experiences raising an exceptional child.

### Fathers Network- Join Parent to Parent's Fathers Network:

Are you the Dad of a child with a disability? Would you like to speak with another father? Would you like to be one of our support parent Dads who make the offer to speak to other parents when they find out that they have a child with a disability? Call our local office at 800-305-8816 or 914-493-2635 or Call Jim Swart, Regional Coordinator of the Father's Network at 800-305-8817.

## Hudson Valley News E-Group:

If you are interested in joining the e-group, please submit your name to [LCarfi@wihd.org](mailto:LCarfi@wihd.org). Your name will be added and you will receive information of special interest including news releases, events, forums, and workshops in the Hudson Valley area.

Our Links Digest is a directory of links to services and information at <http://www.parenttoparentnys.org/Family2Family/Links%20Digest/linksdigest2009-85.html>  
To be added to our e-group and receive the Links Digest each month, contact Laura Carfi.

### **VIRTUAL ADHD CONFERENCE:**

October 5 -7 2009

Now you can get all the tools you need to succeed from top experts, break out of isolation as you connect with peers who've been or are in your shoes and save tons of money by attending from the comfort of your own home participating at your own pace.

Visit: [www.adhdconference.com](http://www.adhdconference.com)

### **The Early Intervention Partners Training Project:**

This project helps parents of young children with disabilities become involved in Early Intervention Program leadership activities. The training sessions provide information, resources, and skill-building activities designed to increase parent advocacy and leadership skills. Parents are encouraged to form working partnerships with early intervention professionals and policymakers.

Parents who are interested in attending must complete and return an application which can be downloaded from <http://www.eifamilies.com>

### **County Websites:**

#### **Dutchess**

[www.dsahv.org](http://www.dsahv.org) Down Syndrome Assoc/Hudson Valley  
[www.dutchess-arc.org](http://www.dutchess-arc.org)  
[www.taconicsources.net](http://www.taconicsources.net)

#### **Orange**

[www.co.orange.ny.us](http://www.co.orange.ny.us)

#### **Ulster**

[www.co.ulster.ny.us](http://www.co.ulster.ny.us)

#### **Westchester**

[www.westchester.gov](http://www.westchester.gov)  
[www.omr.state.ny.us](http://www.omr.state.ny.us)  
[www.nymetroparents.com](http://www.nymetroparents.com)

#### **Putnam**

[www.putnamhealth.com](http://www.putnamhealth.com)

#### **Rockland**

[www.planetrockland.org](http://www.planetrockland.org)  
[www.arcofrockland.com](http://www.arcofrockland.com)

#### **Sullivan**

[www.health.state.ny.us](http://www.health.state.ny.us)  
[www.co.sullivan.ny.us](http://www.co.sullivan.ny.us)

### **Online Support Parent Training:**

If you are interested in becoming a support parent on our network, you can now do the training online.

Go to [www.parenttoparentnys.org](http://www.parenttoparentnys.org) and click on support parent training link. This offers families the flexibility to do the training at their own convenience and pace. A support parent questionnaire can be submitted online or you can contact your local coordinator to receive one in the mail. This must be filled out entirely before you can do the training.

Join our network and help make a difference in the lives of other families. Please call us with any questions. There is also an on-line training for a parent willing to be A Health Care Resource Parent. Check the website or contact Laura Carfi. [lcarfi@wihd.org](mailto:lcarfi@wihd.org)

If you previously volunteered to be a support parent but have not yet completed the training and submitted the accompanying support parent questionnaire, this would be an excellent way to finalize your recruitment and training.

### **Respectful Language Bookmark- Words can hurt or words can welcome:**

Parent to Parent has developed a bookmark to raise awareness of the importance of person first and respectful language. If you would like copies of the bookmark, contact our office or download it at <http://www.parenttoparentnys.org/Bookmark.html>.

**BOOKS BY NEW YORK FATHER ON  
RAISING A FORMER PREEMIE AND SON WITH AUTISM**

Manhattan parent **Jeff Stimpson** knew he had to do something when his first child was born.

Alex Stimpson was born at 27 weeks' gestation and weighed 21 ounces at birth. He spent his whole first year in the hospital, during which Stimpson, now 47, saw his son get a spinal tap without anesthesia, and three times witnessed Alex stop breathing. Stimpson and his wife Jill soon discovered not only how far the science of saving preemies has advanced, but how far it hasn't. "Starting preemies out was definitely more an art than a science," Stimpson says.

*Alex: The Fathering of a Preemie* by Jeff Stimpson (Academy Chicago Publishers, and on Amazon) is the story of Alex's first five years. "My last job before Alex was born was writing op-ed columns," says Stimpson, a journalist. "It wasn't long after Alex was born that I decided that what I was going through was at least as interesting as much of the stuff I'd written about." Stimpson began posting weekly essays about Alex on a Web site, and slowly gathered a readership. "Writing about what we were going through was empowering," Stimpson says, "a way of getting back something I felt I'd lost."

*Preemie* traces the life of Alex from birth to kindergarten. Some of the details are medical – four wings in two hospitals; coming home with a roomful of medical gear and round-the-clock drugs and nursing; the gains and downturns of home therapy through Early Intervention; the diagnosis of autism – and some are episodes any parent can connect with, such as finding a pre-school.

Kirkus Reviews called it "a searing chronicle ... breath-catchingly evocative of life's elemental grace and messy dignity," and the *Idaho State Journal* called it "a gripping and graceful accounting of being a father." Stimpson maintained his writing as Alex grew. Today, Alex is 10 and weighs about 50 pounds. He watches "Elmo", doesn't talk, turns down most food, and sometimes bolts on the street. Now in 5<sup>th</sup> grade, he's just learning to pronounce the days of the week. The only word he can write is his name.

"Before I had kids, I never imagined that one day I'd look at my son and think of *Rain Man*," says Stimpson. "But we're trying everything we can to help him progress and grow."

Stimpson's second book: *Alex the Boy: Episodes From a Family's Life With Autism* (Vervante Publishers, on Amazon and in the bookstore of Vervante.com) offers a glimpse into the feelings and frustrations that come with living with a child with autism. Stimpson self-published *Boy* after his earlier publisher turned it down.

"I'm still shopping the book around," Stimpson says, "but I'm also trying to market it as it is, especially to professors of special- and general education. I speak frequently at colleges in these classes, and both professors and students have told me they find the stories valuable for teaching."

Eating, sleeping, school, Alex as a sibling, public behavior, and other topics are covered in *Boy*, with journal entries broken out by subject. Study questions are included.

Stimpson has spoken at national conferences, and at Exceptional Family Resources in Syracuse and YAI in New York, among others. He also speaks frequently at Manhattanville College in White Plains.

Jeff and Jill do podcasts about parenting a son with autism ("Today's Special," at [jillandjeff.podbean.com](http://jillandjeff.podbean.com)), and Stimpson still maintains the essay site about his family, at [www.jeffslife.net](http://www.jeffslife.net). Jill and Jeff have also begun blogging for the site AutismVox, at [blisstree.com/autismvox](http://blisstree.com/autismvox).

They live in New York with Alex and their typically developing son Ned, age 8. They can be reached at [jeff@jeffslife.net](mailto:jeff@jeffslife.net)

**Excerpts From *Alex the Boy***

"We fear for Alex as he grows up and maybe comes to depend too heavily on a system that was built when there was a lot more money around. It seems that all my life, money has been running out for just about everything but corporate retail. Is there a reason to suppose that a money shortage is going to abate just because Alex is closer to 21 years old than he used to be? To think that these might be the best days of Alex's life." – **from the Introduction to *Alex the Boy***

"He holds the pocketbook-sized flag in front of himself as Jane stands to his right. I can see her whisper 'Stand up, boys,' to Alex. 'Stand up boys,' he says, making the side of his mouth into a comma shape. His classmates stand, some by themselves and some helped by the adult assistants. Alex conducts the Pledge with Jane's help, and he sings the National Anthem probably as clearly as most adults could. Beside me, across the room, Jill sings softly along with him. Since I can't sing, I try not to cry." – **from "School"**

"I put the marker in his hand and make him say the letter before he writes it. I hold his hand with mine, guiding him gently. Sometimes I take my hand away and say, 'You do it, Alex.' He pulls my hand back to his. I pull my hand away. He pulls my hand back to his. 'You do it!' he says." – **from "Homework"**

"His eyes were dull and flickering, and soon they went to the right, and stayed there. I scrambled to give him a neb; he took it in good spirit. But he still retched, his fine pink tongue flexing back and forth. His foot began to jimmy. Jill called for a report, and we were on the phone for perhaps two minutes when I had occasion to say, 'And here comes the vomit!'" – **from "Sickness and Health"**

"Would he still have his sandals on, or would he have taken them off and left them while he strolled on and on? Would people look at him curiously, try to offer him help, ask his name, then give up when he didn't answer? Would anyone try to take him? Would he go? Such a stranger wouldn't have much chance of enticing Alex anyway unless he also had Saltines and happened to be wearing an Elmo suit. My big fear was that Alex would leave Central Park, get out to Fifth, and be plowed down by a car." – **from "Danger"**