



May 9, 2014

VOR Weekly News Update

News and views for VOR Advocates

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QUOTABLE, by Winston Churchill

COMING UP: *The Weekly E-News Update will be going on hiatus until June 20, 2014. In the meantime, you will receive periodic emails from us, including an*

Speaking out for people with intellectual & developmental disabilities



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**Reminders:
Help VOR Grow!**

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Conference and
Initiative:
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Influence.**

About VOR

**Make a Lasting
Impact with a
Will Bequest**

Action Alert on or about June 8 to support the efforts of our Initiative participants in Washington, D.C.

Calendar Reminders

VOR and You

1. Take Action! Tell the Senate not to fund deinstitutionalization

[Click here to take action BY NOON, May 23, 2014.](#)

If not us, who?

2. CARBEN + VOR: Making a difference in style; New clothing company launched, portion of proceeds to benefit VOR

On May 3, 2014, Ben Mettler officially launched his new clothing line company. [CARBEN Clothing](#) is a collaboration between two brothers, Carsten and Benni, hence the name CARBEN.

Carsten is Benni's older brother and was diagnosed with autism when he was three years old. Starting in High School, Carsten started creating beautiful paintings and drawings. Creating art has always been a positive outlet for him. In each line there will be one design featuring [Carsten's artwork](#).

CARBEN's mission from the get go has been to give back to those who cannot so easily speak for themselves and try and make a positive impact in their lives.

To fulfill this mission CARBEN partnered with VOR, which is a non-profit organization that helps people with intellectual & developmental disabilities. A portion of CARBEN's proceeds will be donated on a quarterly basis to VOR. Ben and Carsten's mother, Ana, has

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been a long-time VOR member.

CARBEN Clothing will offer creatively designed clothing that is high quality, feels great, and makes a difference in people's lives. Every time you buy a product from CARBEN you will be making a positive impact in someone's life.

Make a difference in style. [Shop CARBEN](#) today!

3. The 2014 Recipients of the Jordy Engels Award Announced!

VOR joins with our Florida affiliate, [DSI \[Developmental Service Institution\] Supporters](#), Inc.; Ed and Virginia Carraway, VOR Florida State Coordinators; and David and Leni Engels, long-time VOR members, in proudly announcing the recipients of the annual 2014 Jordy Engels Award:

Mike Fasano
Greg Giordano
John Stokesberry

Mike Fasano, retired Florida State Representative and Senator, showed great leadership and compassion for issues impacting Floridians with intellectual and developmental disabilities. He was particularly sensitive to the needs of those individuals leaving specialized care settings to smaller settings, including the introduction of legislation to better ensure the safety and rights of those who faced forced closures.

Greg Giordano, who now serves as Mr. Fasano's communications director, previously served as his chief legislative assistant for most of Mr. Fasano's time with the Florida Legislature. During this tenure, Greg has oversaw the research, writing and presentation of literally hundreds of pieces of legislation over those years, including legislation of interest to individuals with intellectual and developmental disabilities and their families.

John Stokesberry has had a wonderful career of

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serving people, including people with disabilities, including intellectual disabilities, and the elderly. Over his 40 year career he served in multiple professional and volunteer capacities where he advanced the rights and well-being of Floridians with disabilities and seniors. He is also the recipient of the [2005 C. Colburn Hardy Older Advocate Award](#).

Warm congratulations Mr. Fasano, Mr. Giordano, and Mr. Stokesberry, and sincere gratitude for their many contributions to the field of intellectual disabilities and advocacy.

[2014 Jordy Engels Award Recipients Biographies](#)

4. Photos Needed!

VOR is seeking photos of –

1) Your family member(s): Please email no more than three (3) pictures to Harris Capps at hccapps@knology.net, with this signed [photo consent form](#), along with your name and the first name of your family member. Your photo cannot include other individuals unless we also receive a photo consent form for those individuals. If you do not have an electronic signature, your email response will suffice.

2) Photos of your person's residence: Please email up no more than (3) pictures to Harris Capps at hccapps@knology.net. If these pictures include individuals, a [consent form\(s\)](#) is required.

Over time, we will decide which ones to use.

As special thanks to Harris Capps, VOR's South Carolina Co-State Coordinator, who has agreed to help VOR collect your consent sheets and photos for VOR.

STATE NEWS

5. Illinois Department of Human Services and

Owner of CILA (community home) Respond To Resident Walking Away to Murray Center

WJBD News (Salem, IL) * May 6, 2014

A spokeswoman for the Illinois Department of Human Services says it appears that staff at a Community Integrated Living Arrangement (CILA) home followed protocol when a resident walked away from the residence and returned to nearby Murray Center in Centralia late Sunday afternoon.

Jacques says they are willing to continue to work with the former Murray resident despite the incident. However, Jacques says they would not stand in the way of the man returning to Murray if that is determined as the best alternative by the man and his guardian.

Jacques notes a staff member followed the former Murray resident and no one was in real danger. He says like anyone else, the man has the right to refuse medication and they can't force medication down his throat.

[Read more, comment and share](#)

6. Illinois: Many With Disabilities Find Choices Dwindle With Age

Disability Scoop (reprinted from *The Chicago Tribune*) * May 16, 2014

Many with disabilities today are outliving their parents and other caregivers, thriving well into old age. And advocates say Illinois — long at the bottom nationally in delivery of services to those with disabilities — is ill-prepared to meet this demographic challenge.

[Read more, comment and share](#)

AUTISM NEWS

7. Autism Research Efforts Skvrocket

Disability Scoop * May 2, 2014

With some \$1.5 billion in investment, a new federal [report](#) finds that the number of autism research studies has doubled.

More than 11,000 studies on autism have been published since 2009, twice the number issued in the preceding five years, the report released this week by the Interagency Autism Coordinating Committee found.

However, an [investigation](#) last year by the U.S. Government Accountability Office suggested that federal spending on autism research may not stretch as far as it could. Most studies conducted on the government's dime are "potentially duplicative," the GAO found, adding that oversight and coordination between federal agencies is often lacking.

[Read more, comment and share](#)

8. Autism Research & News

AADMD Info Blast * American Association of Developmental Medicine and Dentistry (AADMD) * May 5, 2014

[Genetic discovery delivered by Autism Genome Project](#)

[Connection found between gene mutation and key symptoms of autism](#)

[New research links motor skill deficiencies to autism severity](#)

QUOTABLE

"If you're going through hell, keep going." ~ Winston Churchill

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Calendar Reminders:

VOR Annual Conference Deadlines Approaching:

May 5: Annual Conference Registration Deadline (prices

increases after May 1). Register [online](#) or by [mail/fax/email](#).

May 5: [Hyatt Hotel Reservation](#) Deadline to guarantee group rate and availability. All VOR events take place at the hotel.

[June 8, 2014](#)

[VOR 2014 Annual Conference and Initiative:](#)

"Making it Happen: Reforming Policy and Law in Support of Person-Centered Quality and Choice"; Hyatt Regency, Washington, D.C.

[Register today!](#)

[Week of June 9, 2013](#)

[VOR 2014 Congressional Initiative:](#) Families and advocates visit Capitol Hill.

[Sunday, October 5, 2014](#)

American Health Care Association's 2014 ID/DD Residential Services Day during AHCA/NCAL's 65th Annual Convention & Expo at the Gaylord National Harbor just outside of Washington, DC. Registration information and the schedule can be found [here](#).

[Archives](#)

*** [Thursday, March 20, 2014](#)**

[VOR's "Regional Meetings: The Need for Advocates to Act Global and Local" Webinar.](#)

***Social Media Strengths: Using Facebook and Twitter to Advance Your Cause (VOR, July 2013).** [Visit VOR's website for a copy of the powerpoint presentation and an audio of the event.](#)

*** [How Congress Works Webinar: Recorded - Listen](#)**

[Here.](#) Tuesday, April 23, 2013 - 12:00 pm central / 1:00 pm eastern. How Congress Works: The Basics. Hosted by Peter Kinzler and Larry Innis.

VOR
836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007

Tel: (605) 399-1624
Toll Free: (877) 399-4867
Fax: (605) 399-1631
Email: info@vor.net

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