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December 9, 2011

VOR Weekly E-Mail Update

News and views for VOR advocates

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VOR and You

1. VOR's Nominating Committee seeks individuals interested in serving on the VOR Board of Directors

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We are looking for applicants who:

- Have a passion for our cause on behalf of individuals with intellectual disabilities
- Can commit time for board meetings, committee planning and meetings, and can attend the annual meeting
- Are team players who work well with others in a group
- Listen well and are thoughtful in considering issues
- Are willing and able to assist in development efforts

If you are interested in receiving a VOR Board application form please contact Co-President Sybil Finken at finkensrc@aol.com or 712-527-3250 or Executive Director Julie Huso at jhuso@vor.net or at 605-370-4652.

If you would like to receive additional information from anyone on the nominating committee, please contact:

Ann Knighton, Co-President 706-993-6329

Bill Ryerson, First Vice President WTRyerson@aol.com or 336-765-6763

Mary O'Riordan, moriordan@aol.com or 415-927-0542

Action Center

2. CMS wants to hear from VOR families: Aging in ICFs/MR

VOR is sending this request for information at the urging of the Centers for Medicare and Medicaid Services (CMS):

In CMS' ongoing efforts to improve the care provided to clients in ICFs/MR, CMS is compiling research materials on the topic of aging for folks with intellectual disabilities. CMS is asking families, advocates and others to share any of the following resources you may have. The more information, the better:

- Any recent studies, publications, resource books or literature addressing the aging process as it relates to individuals with ID;
- The names of any national organizations which advocate for the rights of the individual with ID who is aging;
- The names of any Universities currently conducting research on this subject; and
- Any assessment tools that are available specifically focused on the impact of aging on ID clients.

Deadline: Friday February 3.

Please respond to thopp@vor.net. I will forward any information received to CMS. Thank you so much for your assistance.

Sibling's Voice

3. Sibling Features in The Voice * Summer 2011

We hope you enjoyed the winter edition of VOR's member newsletter, *The Voice*.

This edition featured several heartwarming stories that portrayed what families and siblings experience when someone they love has intellectual disabilities.

This week's VOR Weekly E-Mail Update reprints featured sibling articles. We received good feedback in response to these siblings' articles and other newsletter features. One response was particularly touching and we share it here. You'll remember the writer, Saskia D., who contributed her sibling perspective in the spring 2011 edition of *The Voice*, which we also reprint below. For more sibling contributions, visit the Sibling's Voice section of VOR's website.

4. Kudos to VOR

From Saskia D., VOR Member, December 2011 (by e-mail)

"Kudos!

"I find all the voices-of-experience, sibs' as well as mom's, to be a mirror of my own. It is as if, together, they are telling my own story, each adding details which, taken together, represent a much fuller picture. So much commonality!

"My experience of our local groups is that we are so focused on advocacy, we seldom share, emotionally, at the levels conveyed in this issue's articles; and there may be a rightness to that.

"I think for me it takes a certain amount of armoring against the feelings in order to keep going effectively with the advocacy. But reading in the VOICE provided me enough distance to be able to identify without getting mired in my own feelings. I suspect that others may be having some of the same reactions.

"As I was thinking about what I had read, some combination of memory and new awareness began emerging for me. As a sibling, I was totally immersed in my sister's needs, care and development. From a very young age, I was an expert on Kathy, but because so much of my focus was on her, I missed developing in some other areas. Something shifted in me, as I was thinking about that, having read the accounts of the others. My report cards always acknowledged me as bright and, then, went on to say I could do better. I never could imagine how, since I knew I was working as hard as I could. After reading others' experiences in the VOICE, this came into focus for me in a very self-forgiving way: School testing almost always was about what we had been exposed to and retained. My exposure was limited; and my bowl was already full.

"Though the picture may never be whole, if you continue to print personal experiences of family members, I suspect more and more will begin to see themselves as less alone in their feelings, and may also find self-perspectives shifting.

"Thank you! It is a powerful newsletter."

5. Three Siblings' Perspective

By Maureen Durkan, Anne Pichette and Mary Durkan
The Voice *** Winter 2011**

Our "little sister" Sharon is the youngest of seven children, four girls and three boys. She is the light of our lives and has taught us about love, compassion and giving to others. She does not know what hate is; she is innocent, sweet and kind.

Our parents wanted to keep Sharon at home, but she took up most all of their time and they had six other children to raise. Sharon needed 24/7 supervision; understandably, her high care needs were stressing the family out. We suffered from sleep deprivation in those days.

Sharon had one out-of-home placement before she went to live at Fircrest ICF/MR ("Residential Habilitation Center"(RHC)), where she has been since 1974.

None of us will ever forget what a challenge it is to care for our sister who is profoundly developmentally disabled. We don't want other individuals, or families to suffer without proper services for their loved ones. Our state RHCs are a godsend. We need them as part of our continuum of care for all citizens with developmental disabilities to be able to access. We advocate for these services all the time with VOR, Friends of Fircrest and our state organization ActionDD.

Now it is our turn. Read More.

6. Thoughts on a life with Jordy

By Carly Engels Johnston * ***The Voice*****, Winter 2011**

Every parent believes their children are special. Whether they are exceptionally cute, smart, funny, talented in something like music or math, every parent strives to be proud of their children for their accomplishments and their character.

However, what do you do when your child is not any of these things? What do you say about a child who is not capable of achieving anything in life and whose biggest success is merely continuing to exist?

This is what my family has faced. Read More.

7. My Sister Kathy

By Saskia D. * ***The Voice*****, Summer 2011**

I'd like you to meet my sister, Kathy. It used to be that hats and rides were her favorite things in the world, followed closely by treats. Recently, we have had the pleasure of adding dogs to that list.

Fircrest has been Kathy's home for 48 years. As one of Washington State's Residential Habilitation Centers (RHCs), Fircrest has separate licensing as an ICF/MR and a nursing facility. With cerebral palsy, mental age of about 2.5 years, bipolar disease, epilepsy and osteopenia, Kathy is best served in Fircrest's nursing facility. Licensing of Washington's RHCs varies: ICF/MR, NF, or dual. They are incredible resources.

Considering the road that Kathy and I have traveled together to where she is now, at Fircrest, I am thankful every day for all of her compassionate care and the friendships she has developed at her home. Read More.

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