

AMCHP 2008 ANNUAL CONFERENCE

WE ARE MAKING A DIFFERENCE:

Opening Plenary:

A Vision for a Compassionate and Affordable Health System

March 1st to 5th, 2008

NAN STREETER: I have to recognize Ruth's contributions and Rodney's contributions. I can't tell you the first time I met Rodney. And forever remember him being a family advocate. And, of course, Ruth and her tremendous commitment to families is just outstanding. Ruth has been on the board and has been delightful to work with and she has been our conscience about recognizing and involving families. And so she's forever saying don't forget about families.

I'd like to invite Rodney and Ruth to present the first-ever Merle McPherson Award.

RODNEY FARLEY: As Nan mentioned, this is the first year for this award. The nominee of the Merle McPherson Leadership Award must meet the final criteria: Their family involvement in the state program and the association of Maternal Child Health program

increased significantly as a result of the efforts of this individual. Policy and procedures within the state programs and/or the AMCHP have been changed to encourage greater family involvement as a result of this person's work. And this person has actively contributed to AMCHP and the organization's efforts to advance the inclusion of families at all levels.

RUTH WALDEN: The recipient of the first prestigious Merle McPherson Award is a very special man. Bob Cook has served as the Statewide Family Liaison for the Division of Specialized Care for Children in the State of Illinois since 1999. He's worked in the disabled arena for almost 40 years. He, too, is a sage elder.

He has worked and been instrumental in growing the family involvement initiatives in his agency in Illinois where he's coordinator of the Family Advisory Council, editor of the parent newsletter entitled Special Edition. And assists with policy, training and providing direct assistance to staff and families in the state of Illinois with children and youth with special healthcare needs.

Bob first came to AMCHP as a scholar in 1999. Since then he has mentored families at the annual conference for many years. During his work as a mentor, he has empowered the scholars to advocate for Title V after they return home to work in their states.

Bob was a founding member of the family leadership caucus which now has become the family youth leadership committee. At AMCHP, Bob has served on the annual conference planning committee, the governance committee and he diligently urged the adoption of the policy that created two seats for family representatives on the board of directors.

He is currently a state delegate to AMCHP from Illinois. And serves on the workforce development committee. Bob and his wife, Chris, who is here with him, live in Taylorville, Illinois, and are the parents of three children. Their daughters are Elizabeth, age 26, and Caitlyn, age 11. Their son Seth had multiple severe disabilities and died in 1999 at the age of 15.

Seth was enrolled in the Illinois Title V home waiver program for 11 years. And it is my pleasure to introduce Bob Cook.

BOB COOK: Thank you. I just to say ditto from my other award winners that it is truly an honor to receive an award from your peers.

I first want to acknowledge my journey, especially with my wife Chris who is here and Caitlyn. When you have a child with special healthcare needs, your partner becomes very important in your life. And so I want to personally say thank you to my wife, Chris.

Sometimes the journey is not that smooth. But I knew we were in it together and I know we would come out good at the end.

I want to thank Rodney and Ruth for their support through the many years that I've been involved in AMCHP, and I especially want to thank Dr. McPherson. It truly is an honor to be the first recipient of this award.

But I know I'm not up here alone, because the award isn't just for me. It's for all the families involved in AMCHP and Maternal Child Health.

When I first came to AMCHP in 1999, it was two months before I started my job in Title V. And Dr. Onufer, who is here in Illinois and I want to thank Dr. Onufer for his support and

encouragement throughout the years. When I was hired as the first parent in Illinois, they basically gave me a clean slate to develop the program the best way.

And one of the first things he did was nominate me for a scholar. And I want to thank him for that. Because it was through AMCHP over these many years, eight years now, that I met many wonderful people who have helped me along on that journey.

Not only the families, but a number of professionals throughout the states who I've learned from, like Dr. Hollingsworth in Rhode Island, who has a wonderful family program, and for so many others.

It truly has been a wonderful journey so far. You know, I want to mention that there is a politician from Illinois who is on TV a lot. And sometimes mentioned problem with plagiarism so I don't want to get this quote wrong. one of my favorite quotes was from Robert Kennedy who used the Winston Churchill quote that some people see things as the way they are and ask why. And others see things as they could be or should be and ask why not.

And for many of us family members, that's what we do. We are that conscience. We always ask why not, why not have family members on the board. And I might even mention to Mike why not have a family member on staff.

So it is a truly -- So we still have a long way to go. We have made many strides and we can see real hope. I like Mike's quote. And as I'm writing my notes, Mike mentioned the aim high. And I think that's what we as family members try to do. We need to keep aiming high.

You know, at the state level I want to encourage my fellow delegates to go back and get families as delegates at AMCHP so we can be more involved. I want to make sure also, too, that the state Title V programs continue to increase their involvement with families at whatever level.

I'm still amazed that still a number of states have not fully incorporated that. And I strongly encourage them to do that.

I also want to encourage and thank AMCHP. You know as I mentioned, my coming to this conference has meant a lot. My involvement in the committees. My involvement in just

meeting with so many families has truly changed our program in Illinois. Hopefully for the better.

But my final challenge is to the families here today and especially those 10 family scholars, where are you? Can you stand up for a second? The family scholars.

I was in the same boat back in 1999. So I want to give you a big challenge: AMCHP has created a program which they really incorporate of opening doors for families. So I really want you to make sure you go through that door, but not only go through the door but grab a chair and sit at the table and start talking and asking why not.

It's very important that we make everyone aware of so many of the issues that families face. And that we are an integral partner within the program.

So on behalf of my family, including my son who I know is with me right now, I want to thank you for this award and look forward to seeing other award winners in the future.

Thank you.