**Traumatic Brain Injury/Brain Injury Association of America**

**State Legislation Round Up**

September 22, 2004

GEOFFREY LAUER: Good afternoon. And welcome to the Brain Injury Association of America which is legislation dealing with brain injury in the states. I'm Geoffrey Lauer, the director of the affiliate relations of the Brain Injury Association of America and joined by other colleagues around the country who I'll introduce in a second. First of all some thank yous. Thank you to the Maternal and Child Health Bureau for their support and the technical assistance Center for helping coordinate this and to the University of Illinois at Chicago for their technical support for this webcast. Another thank you for presenters today who have taken time out of their afternoon to get a handle on some of the exciting legislative options that happened this year. On your window you'll see a Power Point presentation we've put together. The slides will appear in the central window and advance automatically. The slide changes are synchronized with our presentation so you don't need to do anything to advance the slides. You may need to adjust the timing of the slide changes to match the audio by using the slide delay control that you'll see at the top of your messaging window.

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where you're participating from. These questions will be relayed on to the speakers on occasion throughout this broadcast and if we don't get the opportunity to respond to your question during the broadcast, I'll make sure we email you directly afterwards. We encourage you to submit questions at any time during the broadcast. On the left side of your visual interface is the audio window. You can adjust the volume of your audio using the volume control slider which you can access by clicking on the loudspeaker icon. For those of you who have selected the accessibility features when you registered you'll see text captioning under the video window thanks to the captioner located in Hudson, Wisconsin.

The interface will close automatically and fill out an online evaluation. Please take a couple minutes to do so because your responses will help us plan future broadcasts and improving the technical support. That's it for now and without further adieu I would like to introduce our panel today. We have Cheryl Spencer with us who is the chair of the Brain Injury Association of Tennessee. Stacy Rye, executive director of the Brain Injury Association. Tom Gode who is the executive director of the brain injury association of Minnesota, Miryam Miller, new executive director at the brain association of New Mexico and finally executive director from New Jersey is Barbara Geiger-Parker. Today's legislative roundup, and the focus today is on trust funds and other dedicated funding streams. We'll be touching base on some other appropriations and if we have time on other efforts.

The goal today is to give you folks out there in cyber world live a snapshot of some of the exciting things that have happened over the past year but also to encourage you and people who might Mott be on the webcast today to reach into the archived version of this webcast and share this with your boards of directors and other legislative advocates to try to continue to keep that grass roots movement energized. Next slide, please. So relative to trust funds and other dedicated funding, most trust funds and funding streams are established through legislation. The primary source for these funds are from fees on speeding, reckless driving, D.U.I., driving under the influence, and other civil convictions. The rational for that is the number one cause for brain injuries is still motor vehicle crashes and the people paying for these services to brain injuries are the individuals who put themselves or others at risk of brain injuries.

If you don't want to pay for services, don't speed. If you don't want to pay for services, don't drive drunk. If you'll do those things the reality is you pay more in fees or registrations for that. That's not 100% across the board. We'll hear a couple of examples where the trust funds are funded through some other manners but that's one of the main rationals. As the third bullet there says, sometimes these are funded through surcharges on auto license tags, drivers license and firearms registration. Next slide, please. Trust fund legislation often also establishes an advisory committee for general oversight. And coincidentally many states have an advisory council that is part of the national traumatic brain injury effort to establish four core components in each state for system change and sometimes those advisory committees and the brain injury advisories councils are one and the same. Trust fund legislation designates a state agency for the fund and for that

fund programming and service administration. In addition, legislation can stipulate that the trust fund shall be non-reverting which means, to the best of my understanding, if there are any unexpended funds at the end of the year, that they roll over into the next year to be spent just for these brain injury services and it cannot be reached in by the legislature to backfill rural roads or other issues. Thank you for bearing with me for a brief overview of trust funds.

At the end of the presentation I'll direct the listeners to some resources where you can get more in-depth trust fund 101 information at the brain injury site as well as the website of the National Association of helped injury administrators and have the links up on our star site. You won't be able to swing a cat without finding one of the websites. Cheryl from Tennessee, share with us a little bit about H.B.779.

CHERYL SPENCER: Thank you, Geoff. I appreciate that chance. Our initial legislation was passed in 1993 and as you indicated, it did establish a TBI fund and council. The prevailing agency for that is the Department of Health. Now, the -- that was based on funds that came in from four different fines, basically the ones that you mentioned. And that fund initially brought in quite a bit of money. I think about a million half. Which was quite a bit of money for Tennessee, anyway. What happened is apparently there has been -- we haven't quite been able to pin this down. There has been some change in the way that either the funds are categorized or some way in the bookkeeping is going to change. What the result of that was that about the last five or six years the fund has

dropped down to just about $700,000, which did not meet our programmatic needs. As we saw that coming we started to introduce our legislation in 2000.

Our initial legislation came with Senator Curtis persons who was the original sponsor and he was a bulldog to help us get that passed. Since those years we have very much cultivated that continued friendship with him. When it rolled around to be time to look at going to the coffers for more money. Though he didn't sponsor the bill, he did a lot of background work for it in order to prepare for its introduction. In the meantime we made a new friend with representative Bob Patton from east Tennessee and in the voting district of June Barrett, the founder of -- she was on the board and set up an advisory committee for a strategy to handle this. June headed that up. The executive director of -- Jean Doster was also on that as was -- I was also. In our initial meeting the one thing that we agreed on was that we needed to have support from all parts of the state.

Tennessee is like three separate states and we fight with each other all the time. And we realized that we were going to have to have that three-speared coverage in order to really make this work. So that was really the major effort that we concentrated on was to make sure that we had everybody -- every part of the state on board and so each one of us took an area of the state and we contacted our legislators and started cultivating those friendships in order to make that happen. June Barrett really went to work and she pushed, she pled, she did whatever was necessary in order to make that happen. And Jane Andrews, who is our TBI council chair lived on the hill. We had a lot of presence in the committee meetings. D.O.H. has a legislative liaison they made available to us so

that he fielded questions, he referred, he got us appointments and so we had somebody who really was present up there and had a lot of good contacts the press all of this forward. And my personal responsibility was to get our -- our support groups, of which we have 12, to get those people writing letters, making phone calls, honking horns, whatever it took to bring attention to the fact that we had a lot of people in Tennessee with traumatic brain injury that aren't getting services.

That was the background and then just a couple of days before the vote was to be taken, the Knoxville support group had taken the initiative to produce a video. And in that video we presented the case, all of the speaking points that had been pretty much sent out spearheaded by Jean, we presented those and then we had interviews with four survivors and their families talking about what the council -- what the funding from the council had done for them and what their continuing needs were. And we got a very, very good response to that. And the upshot of it was that the legislation was passed with only one negative vote. A little sidelight is we had a particular Senator who was -- representative, I believe it was, who was adamantly opposed to passage of the bill and in favor of repealing the helmet law. We think maybe he's had a brain injury or whatever but -- we had some real problems with him and, in fact, when Mrs. Barrett presented, he was quite adversarial and insulting and was reduced to tears and had to withdraw and I think that ended up being -- it elicited so much response from the people that were there that he ended up being an ally without intending to. You never know what might be on your side without intending to be. That's pretty much the story. We ended up getting it passed. It looks like

it will about double the income that we've been having from the fund over the last five years.

Our next effort will be to -- we'll start targeting judges to make sure that the fines are being levied and we're also approaching the -- I'm not sure which department it is that's keeping track of statistics as far as the collection of the funds to find out what has changed. If we could get back to the former correction and the addition of the new funds we'd have a nice pot of money to work with. That's Tennessee's story.

GEOFFREY LAUER: I've got some questions in but I'm going to hold these for the end, if that's OK. Our next presenter is Stacy Rye, executive director of the Brain Injury Association of Montana. Thank you for being on board today and sharing with us how you did what you did.

STACY RYE: Well, thanks for putting this together, Geoff. It helps a lot to take back to our board of directors to see how other states have done it. In fact, the way we started was we studied a couple of different states and what they had done in the past. This was the beginning of the end of 2002. The Montana House of Representatives only meets every other winter so you have a three-month shot at bringing forth legislation every 24 months. And so we looked around on different websites about New Jersey, Michigan and a couple of other states, what they've done for legislation. And kind of got together several of them to bring forward to my board of directors and they voted on bringing forth legislation that would enable all drivers in Montana to check off a voluntary time donation

to help fund education and awareness and prevention for brain injury in the State of Montana. The reason why we made it voluntary and why the representative took it forth like that was because of the political climate at the time in Montana. I think that part was pretty important. It was a close vote on the board of directors whether or not to take it forward as a mandatory dollar or a voluntary dollar.

We have about a million cars in Montana so it could raise upwards of time million. We went with voluntary because of the political climate. It was the first legislation to do anything with brain injury in the state to date was in 2003. So we thought we would get our foot in the door like that. When the political climate changed maybe we'd come back in a couple of years in either one or two sessions with additional legislation. I think we're going to do that. So we had a representative bring forth the legislation that sponsored the bill. She happened to be the wife of a podiatrist and she was a bulldog. She went through the process works in most states that it went first to a committee with the House of Representatives, it passed through committee, it went to the House of Representatives and a Senate committee. The full Senate, and then it went to the governor. So it had five big steps. And a bunch of small steps within all those steps and we testified to both committees and I -- the office here got together about 50 to 75 people that turned out to be the core group of people that either went and testified or called, made phone calls on days it was being voted on, or wrote letters. And because we're such a rural state, representatives are very closely tied back to their districts so I was very careful in this office to identify representatives who might be possible swing votes depending on their district. And called people in that particular district to reach their representative.

The most amazing part of it was watching a group of people in power, representatives, have -- they had undivided attention, the people with disabilities that went and testified had the undivided attention of people in power. That was probably the most amazing thing in the entire process. We had at least one Senator in tears. We had both committees applauded. And there is an entire protocol that you have to follow on how to address the representatives. Of course, the office went and presented data, but we kept it very short. We kept it five, ten minutes. And the people with brain injuries went forward and said look, if I had known about information, knowledge, education, when I first had a brain injury I could have gotten services right away instead of five, ten years down the line. It passed with flying colors. We had an entire group of people went to the governor's office and took pictures while it was being signed. We had surprise lobbying groups show up that we didn't contact and they showed up on their own.

Trial lawyers, nurses association, medical association and a couple of others showed up on their own and testified for it as well. It was the survivors and family members going forward and testifying that made the difference. Both committees at the outset said you have 20 minutes to testify and we ended up being there for at least an hour half both times. And so that's what we did. Let's see, the bill is attached to the Department of Health and Human Services. It did come with a governor's advisory council to oversee the fund. The Brain Injury Association of Montana isn't directly connected to the funds but we can apply to the funds when the pot gets a little bit bigger. We considered that very carefully, too. In hindsight do I wish we would have done anything differently? I don't

think so. We didn't want to make it look like in the political climate we had we didn't want it to look like that the Brain Injury Association of Montana wanted it only for themselves and there is no other group in Montana doing what we're doing. There are groups doing somewhat similar things with group homes or assisted living or something like that and we wanted those groups to be able to take advantage of that pot of money, too. So I do think this year now that we have our foot in the door, we're a little bit more savvy and have more experience we'll bring forth another bill that is based on Minnesota's. And we'll see what happens with the elections this fall to the political climate in Montana and the one last piece of this is that I think it really motivated a lot of people to become a voting block in Montana.

People with brain injuries realized how important the process was and realized how close they really are to their representatives. It was a great civic process and it was delightful. Our office was a disaster for months because we would spend literally eight, ten hours on the phone calling people saying please call your representative. His number is this. This is what you would like to say. We came up with a sheet of talking points but we just let people talk and be themselves. And that turned out to be the best thing. We just kind of provided the skeleton of an organizational structure in which to move through and then we just had people go forth. So -- some people really enjoyed it and I think will probably be involved more. It doesn't matter if you're someone with a disability or not. The political process really turns some people on. So that's about it.

GEOFFREY LAUER: Stacy, this is Geoff. We have a question here that says, we know that the Brain Injury Association of Montana is a rather modest office. Did you use volunteers or how were volunteers used in this process?

STACY RYE: It was all volunteers.

GEOFFREY LAUER: All volunteers.

STACY RYE: It was all volunteers. The office staff got paid for the days that they worked on it. We had people throw money in a hat for people that couldn't afford gas money or bus tickets to our state capital in Helena. We had a lot of donations. I would call people and said if you can't come testify can you donate $15 for gas so, so and so can come. It was all volunteers.

STACY RYE: One more question in terms of, what did you find the biggest challenge in terms of the administration or the coordination from a grass roots perspective?

GEOFFREY LAUER: The biggest challenge was probably -- hum.

STACY RYE: The biggest headache.

STACY RYE: The biggest headache was not knowing when the bill would be heard. We often had at the most 24 hours notice of when the bill would be heard or voted on. We didn't have any more time than that. So you checked the Internet that went through the legislative steps. There are about 32 of them. You checked the Internet probably once every half hour for about three months to see where -- if anything just got posted. Gratefully in Montana they post those things right away. They have to because it's so far away that's really how people keep up is by the Internet. And so when something came up and it was at step 23, that's when we would fly into action and try to, you know, make 10,000 phone calls within the next eight hours. Sometimes we were making phone calls at 10:00 at night.

GEOFFREY LAUER: Thank you. Stacy, I know you aren't able to stay on for the entirety of this call but very much appreciate you taking time out of your busy conference season and working with us.

STACY RYE: Thanks for having us, Geoff. Good luck to all the states that try to do this. Thanks, Minnesota, too.

GEOFFREY LAUER: There you go. I'm going to ask to move to New Mexico next, actually, because Miryam Miller is here with us. Are you there?

MIRYAM MILLER: Yes, I am.

GEOFFREY LAUER: I wonder if you can give us a little background on what truly is known nationally as one of the most successful initiatives this last year, the faces of brain injury campaign in New Mexico, it got great visibility and it was very impressive. I'll leave that to you.

MIRYAM MILLER: Yes, thanks. Let me just say it was my first year up at the legislature so it was a fantastic learning experience for me. And just how lucky that I was to be a part of such a remarkable thing. I'll give you the punch line first, I guess. In New Mexico we have the brain injury advisory council and a trust fund set up that covers acute needs during the transfer time from rehab into the home. But what we are missing very much is long-term services for people with brain injury. And we have waivers set up for folks with disabilities, but most of the people with brain injury either don't qualify for those waivers or don't get their needs met through them. So last year at the legislature we moved forward with the brain injury waiver bill and we asked for $2 million from the general funds to be matched by $6 million from the feds for the Medicaid waiver. And the reason, I guess, that it's well-known and so remarkable is that the bill passed unanimously in the house and the Senate and -- but was ultimately vetoed by the governor.

So -- I'm going to cover this in a minute, but I was there when people were giving testimony and they said is there anybody here to support this bill and there were 75 hands that went up in the room and it just brought tears to my eyes. So the way that this worked was really a combination of having the good luck to have someone who was very savvy at the legislature and really did some work, you know, for five years, in coming up to

presenting this bill. And then a phenomenal interface between the person who was working with the legislature and that was Rachel O'Connor, the former director here at the brain injury association of New Mexico and has gone on now to work -- she not only worked with the legislature but brought such mobility to the brain injury community like you would never believe. The third component was the media and public awareness campaigns that were happening. I won't give you the ten years of background, but I'll just cover those three areas and kind of hopefully explain what happened.

With the brain injury association and the brain injury advisory council working together and also what -- we have the HRSA grant which was located at the Department of Health and then moved over to the aging and long term services department. We were able to train a class of 25 individuals from the brain injury community who came together for three weekends and were trained as advocates. They learned about brain injury, they learned about the legislative process. They learned about Medicaid and Medicaid waivers and they gave practice testimony at committee hearings -- mock committee hearings and practiced with speaking to their legislators. It gave a group of people who were fired up and ready to go. And then the work Rachel did a lot of fantastic work choosing sponsors for the bills. We had -- we presented the bill in the House and the Senate to the same version of the bill in each house. With legislators who were, you know, very well respected and in leadership positions. And the bills were presented early and then there was flexibility throughout the process. When the bill was kind of getting hung up in the floor of the Senate, we had some help from the legislators to move the bill forward from the House. And so we had flexibility throughout the process.

The big thing that happened was that Rachel developed support from many different avenues. The brain injury community in particular, there was a lot of effort towards education for individuals of brain injury and their families to be able to participate in the process and then other interested professionals, including people from protection and advocacy, the independent living resource centers, the two major rehabilitation hospitals in the state, the AHRQ, case managers. We had lots of work at the support groups and we have a small clubhouse in Albuquerque and then that leadership group that I mentioned that was trained through the HRSA grant. There was really mobility in the community that was quite phenomenal. The leadership group went forth and contacted their legislators personally during the interim and that imagine a huge difference. We had legislators at the committee meeting saying oh, yeah, somebody met with me in my office about that. And then when things were getting hung up in the process, we -- Rachel would call the -- one of the constituents from the advocacy training group that belonged to the legislator where the hang-up was happening and she would give a call and it made a huge difference having this really active group of advocates.

It created just a lot of buy-in so the brain injury community in New Mexico was speaking the same language and we were all very clear that the problem in New Mexico is that there is a lack of long term services and we had a fact sheet that was printed and it showed the statistics of occurrence in New Mexico and described the brain injury waiver and why it was necessary. Then we also had a phone tree, as Stacy described in Montana. And we had volunteers coming in and the tree spread its branches and one

group of people would contact the next group of people and people were really kept up to date on a moment by moment basis through the phone and through the Internet. And then the last component was the media and public awareness. That's where the title of our slide, the faces of brain injury, comes from. We put together a packet of post cards and then a booklet that had seven individuals with a close-up shot of their -- of their portrait and then it told their story beneath it. Gave their name and told their story of living with brain injury. The post cards we printed and we sent to the legislators every other week leading up to the session. So it really gave a personal look and a face-to-face contact even though it was on paper. Then we used that as an opportunity to bring some press.

We held a reception to introduce the faces of brain injury and invited the press to come and got some good news coverage with that. We also -- Rachel was able to capitalize on local events that happened in New Mexico. We had an officer that was shot in the head by an individual who had an undiagnosed brain injury. She, of course, got a lot of press and the brain injury association worked with her to mention the needs of the -- the long term service needs of people with brain injury. Carol came up with us to the legislature and testified on behalf of the bill and she was in the midst of rehab and the legislators knew her face and her story and also the advocates who were coming up to testify knew her and it was like hob knobbing with a celebrity and it really moved the bill forward as well. We utilized the list of the advocates to kind of inundate the media in response to pertinent stories. When a story came up we had a reporter write a fantastic story about a bill called the bill of hope.

All of our community wrote letters in and said -- told their story of brain injury and how the bill would be helpful to them. And the legislators here and in particular the governor, is very impressed with the news coverage of different things, so that helped us as well. Let's make sure I've got everything. Really, the thing that made the difference and the reason that the bill passed, other than the phenomenal work of Rachel O'Connor at the legislature, was the number of people who just came and attended. And just like they described in Montana, we just asked people to come and tell their stories and the legislators gave us a lot of leeway with protocol. And at one of the committee hearings, no less than 25 people got up and gave testimony. It was unheard of. The legislators were crying and we were crying and people with brain injury showing up and participating in the legislative session and sharing their stories is the most powerful thing, I think, that I've ever seen. I think that's what has made the difference here in our state. Thank you for letting us tell our story and I hope I got the information to you clearly.

GEOFFREY LAUER: You did, thank you very much.

MIRYAM MILLER: Sure.

GEOFFREY LAUER: There is a couple of questions here because I know that you need to leave early today, too.

MIRYAM MILLER: Yes.

GEOFFREY LAUER: This is a question from one of our state affiliates that says, we've heard about some of the materials used for the faces of brain injury campaign. For example the post cards. Is there a way that state affiliates can get examples or temp plates of those?

MIRYAM MILLER: I think there is. I'll have to double-check the copy rates but I believe that we have ownership so it doesn't -- I think that's OK. And I can-

GEOFFREY LAUER: If it turns out it works for you I can help get it on the website.

MIRYAM MILLER: People can email me as well.

GEOFFREY LAUER: At the end of this presentation your email will be one of the slides.

MIRYAM MILLER: Great.

GEOFFREY LAUER: Great. Thank you so much.

MIRYAM MILLER: Sure. Thanks very much for letting us talk. We love telling our story here.

GEOFFREY LAUER: You do a great job and a lot of states like to hear the stories because this is what makes it work. If we can go to the slide on Connecticut, I think that is slide number 8. Thank you. Julie Peters will talk to us about what has worked in their state.

JULIE PETERS: I'll start with a brief history to show you a little bit about why we chose to do this. Currently about 40% of our revenue is generated from a Department of Social Services grant. In recent years it's been well over 50% of our budget has come from one source. As our state has had more and more financial problems, we've seen the money that comes to us has decreased significantly over the years. And so with that was our ability to provide services as we became smaller and weaker, we reduced staff and services. And so we were looking at a way to provide the brain injury association of Connecticut with a more stable source of funding. In November of 2003 the board of directors voted to contract with a new lobbying firm with the goal of getting legislation passed which would provide the more stable source of funding. I should say I was opposed to the decision.

The board voted to retain our long time lobbyist as a cost of $15,000 and to hire a new firm which would only take our contract if we maintained our current lobbyist and they would charge us $30,000. Our budget at that time included $4800 for lobbying expenses and the board voted to spend $45,000. With no plan for raising the funds I was concerned about our ability to do it and our long term survival. The firm was hired because they're the largest and strongest lobbying firm in Connecticut and very strong personal ties to our

governor.  Just after we hired them the governor began his own downhill slide with corruption and the tie was no longer as helpful but we already signed our contract.  In preparing to submit the legislation we looked at what other states had done and spoke to people in Massachusetts, New Jersey and others to learn what worked and didn't work for them.

In January of 2003 we introduced Senate bill 942 which would have assessed a fee on speeding tickets and D.U.I.'s and reckless operation.  It was estimated the fund would generate time.9 million annually.  It was a year where the state was trying desperately for the state to save money.  We showed how grants to our organization and others could be cut or reduced by being funded through this program.  Secondly, we told them why assessing motor vehicle violations made sense and finally how other states had done this successfully.  We hosted a luncheon for legislators to inform them about a bill and kept up an email list of our supporters, board members and others willing to contact their legislators.  Dozens of survivors and family members, professionals and board and staff attended the public hearing when the bill was introduced in the public health committee.  I would agree with both Montana and New Mexico that was really important.

The testimonies were incredibly well received.  The bill sailed through the committee.  It went on to pass finance, appropriations and judiciary.  It was from those committees to the Senate floor where it died after being moved to the dreaded foot of the calendar.  We were told a major problem with the legislation was that legislators aren't opposed to it, we didn't have any single powerful legislator who was passionate about it.  We needed someone to

make it their personal go to carry it through and were told legislation never passes the first time through and that it would take two to three sessions. After negotiating with a reduced rate with both our lobbyists we began again this year. The finance committee said we should reduce the amount of the surcharge and only ask for what we as an organization minimally need. Since we had been vague about the ways the fund could be used they said we should start out smaller.

My advice to other states is if you want to go to -- for a more significant amount, be clear as to how you see the funds to be used. We didn't have a good plan for spending the 01:14:11.729 million. Because many people think that motor vehicle fines in Connecticut are far too high already it was also thought that legislators would be less resistant to a lower fine. We rewrote the legislation to assess a $5 fee on the speeding, reckless driving and D.U.I., an account would be established in the general fund and the money allocated to the purpose for providing grants BIA of Connecticut. The balance would be carried over until the next year. All money goes to BIA and D.S.S. can't switch the funds to another organization.

GEOFFREY LAUER: I want you to re-emphasize that. Did you just say that the funding is dictated or determined to go to the BIA of Connecticut?

JULIE PETERS: Correct. We also reduced on the slide it says to conduct education, information resources. That all was eliminated as well and simply there are no strings attached. It is allocated to the Department of Social Services and the purpose is to

provide grants to the Brain Injury Association of Connecticut. They can't use it in any other way. We felt that was a huge, important part of it as you just said. We then went to the governor's secretary at the Office of policy and management. In Connecticut he's the governor's closest associate both personally and professionally. He holds the purse strings. Last year he didn't support the legislation. He didn't have anything against us but is opposed to any type of off budget dedicated funding.

Our lobbyists were able to get a personal meeting with him. Our president, both lobbyists and I explained the importance of the legislation. We ended up gaining his commitment he wouldn't oppose it. That was significant in our state. This time we introduced the bill in the finance committee with the two members that had supported it and that we had talked to about the bill. We had once again a very good group of supporters who attended the hearing but this time since the public hearing was held in a committee that had many bills that they were looking at at the same time we ended up not being able to get as many people to testify as we would have liked. We only had about five people actually to get on the bill because it was going late into the evening as people were testifying about other bills. But again there was very little opposition.

The bill passed both finance and the judiciary committees. It was at this point we realized we were going down the same path we had done last year and likely to get the same result. We still had no passionate supporter for the bill and so our lobbyists got together and through some of their valuable connections with Senate leaders decided to go in a new direction. The language of our bill was added as a very small amendment to a large

transportation bill. This bill had no real opposition. It was basically a housekeeping bill with some revisions to some D.M.V. statutes. We were a tiny piece of the bill. We allowed S.B.558 to die and we were attached -- it was a 35-page bill and we were the last couple lines of this enormous bill. At this point we also totally switched our approach. Now we did not want to call attention to the amendment. We didn't want to have people contact their legislators.

We didn't want the legislators who had their own pet programs to try to disrupt the bill. We basically wanted at this point to fly under the radar. So after the bill passed in the Senate it was scheduled to be voted on by the house on the second to the last day of our legislative session for the year. The day before the vote we hit an obstacle. The motorcycle association got word it was in the works and were telling legislators not to pass the bill because of the amendment. The bill was too important to mess up. If they got any opposition at all they'd pull our amendment. Within an hour of receiving word of the opposition we faxed a letter to the speaker of the house assuring him we wouldn't used funds received as a result of the legislation for the purpose of advocacy to change the motorcycle helmet law in Connecticut. I was careful on how I worded that because we have other ways we receive funding but we would not use this funding for any kind of advocacy for motorcycle helmet laws. At almost midnight May 4 the house passed the bill and the governor signed it into law June 3.

What lessons can I pass on to you? Be careful what you ask for. While this fund is not going to produce the kind of income many states have. It is estimated it will produce

$365,000 a year.  It also passed because it was considered such a small amount.  It wasn't large enough to get any large red flags with it.  I would also suggest that you maintain a clear and focused message as to why the funds should be allocated as you have outlined.  Particularly in our first year we found legislators trying to attach pet projects not related to brain injury to this fund.  Get the committed support of at least one powerful legislator.  They need to be in a leadership position and need to have the ability to push legislation through.  They also need to be passionate or made passionate about the issue.  Consider your lobbyist carefully.  We're fortunate, having spent $60,000 in two years this will result in long term benefits.  While our long term lobbyist is excellent and did much of the leg work on this.  It was the connections that the powerful lobbyist had that it worked.  I don't think it would have happened without both firms in our case.  As everyone said get your supporters involved.  I don't think we did a good enough job in this.  In the future I want to see us do a better job of finding those interested in legislative advocacy. Connecting with them better and getting more people interested in it and connecting with them.

My favorite lesson comes from the testimony I watched on TV may 4 before midnight when a legislator was asked why the Brain Injury Association got the funds was, because they asked.  Don't be afraid to ask.  Get organized.  Get influential support and advice and don't be discouraged if it doesn't happen right away.

GEOFFREY LAUER: One of the questions came in that said why did the Brain Injury Association of Connecticut feel they were justified in getting themselves written into state legislation. And I think you just basically said, don't be afraid to ask.

JULIE PETERS: Thank you.

GEOFFREY LAUER: One other question that came in and I think you may have answered this but it came in, is what would you say the balance -- was the balance between the advocates. The mobilization of advocates, versus the bulldogs, the people who were doing the strong advocating or lobbying, which was the key to success?

JULIE PETERS: In our case because of -- we would have never thought -- I would have never imagined to switch tactics this way and to then put us as an amendment and basically hide us. Our lobbyists were the ones who figured out to do that. They had the connections and support of the speaker of the house, which was huge. He was willing to do that as long as he didn't get any flak from anybody. In our particular case, while the grass roots effort was incredibly important as we went through the whole process, in the very end it would have never happened if we didn't have the lobbyists that we had who were able to figure out a way to sneak us in, basically. That's what we did.

GEOFFREY LAUER: What were the specific arguments used to justify having the Brain Injury Association of Connecticut written into law. Susan Connors from Washington, D.C.

JULIE PETERS: In the very beginning what we were trying to do, we used it as we're looking at a way to save the state funds. As I said earlier, we get about $130,000 grant a year from the Department of Social Services. So we went at it from why us? Because we'll save you money. Granted in the whole scheme of things that's a tiny drop in the bucket but it was one of the things that we talked about. Also, we are the organization in the state who is providing education, information and resources to people with brain injury. Frankly, when we looked at this in the beginning, we wanted to do, as I think Montana talked about, being one of a number of organizations which would benefit and certainly having money go directly to people with brain injury. When the money is such a small amount, you have to start somewhere. And so I think in our case going to us because we're someone who already gets state support and the whole rational of why us also being that the relation of motor vehicle violations to brain injury and that type of thing.

GEOFFREY LAUER: Thank you. Thank you very much. All right. And I very much appreciate you staying on board, Julie. I know you have things to go to so we'll move on. We have three more states that we're going to be focusing on today. Florida, Minnesota and New Jersey. And so from the slightly beat-up State of Florida and since it's just about time for Thanksgiving we'll learn about what a turkey is.

ELYNOR KAZUK: Thanks, Geoff. Just as a little background. Florida has had a trust fund since 1989. And B.I.A.F. did help to get that established with the grass roots efforts that people described earlier. And we would get funding from that fund at this point up to about time up to $1.2 million in contracts. It is administered by the Department of Health

and we're considered partners with them and it's a very good relationship. We provide what they do do in regard to long-term care even though, as others have said, the legislation itself does not really cover that area substantially or it's not supposed to in any way and they just squeeze it out of there. However, we do get a lot of money from the fund. The fund itself is a $15 million a year type of fund from drunk driving and speeding tickets. I'm laughing because it sounds as if we must have an awful lot of drunk drivers and speeders in Florida to get that kind of money.

GEOFFREY LAUER: Well—

ELYNOR KAZUK: But anyway, what we do is to help fund these contracts by legislative activity that is called a member project request process. It's something we've been doing for the past six years and it's been very successful for us. But it's an appropriations process versus the process of getting a bill passed. Now, a member project request, some states call them pet projects, some states call them turkeys. The federal level they're called pork barrel-type things, earmarked projects. You get the idea here. It's a process that is open in the State of Florida to the public. It's available to anyone. And it's very nice sounding in that anybody who has an idea can write it up in the proper paperwork and submit it to their legislators or anybody they can find in the legislature who will sponsor the project for them. You need a sponsor in the House and a sponsor in the Senate. I say it's open and available. But the reality is that it's very -- our lobbyist says, serious, it's behind the scenes and the process itself is not easy to figure out in how you

actually get committees and committee chairs and so on to appropriate the money to you in the budget.

The governor -- our governor now, discourages these kinds of things and says he's not going to fund them. It's not right. He would rather not fund them at all. It's been done for so long and it is part of the process that I think goes on in every state and so we do it. But as someone said before, you have to either have a lobbyist or some powerful support that can get it through and it is not the thing that can be done through grass roots kind of efforts. We hire a firm that specializes in appropriations. We pay $1800 a month plus expenses and we've been very successful in getting our projects through. Every year we fill out the paperwork, we get help finding the right sponsors and we have one person in the Senate that has been doing it every year but every year we ask for $785,000 for our family support project and that would fund ten family support centers across the state. And this year we asked for a couple hundred thousand to do more work. We had two member project requests. Five years ago we asked for $785,000 and got $300,000. The next year we asked again and again. We ended up with $300,000.

This year it went on like that and this year we were very, very lucky to get the entire $785,000, plus the second one for the prevention program that we put through. So once it goes through that same committee process and once the governor signs it, it is in the budget and it gets sent over to the agency where it is -- where it belongs. We work with the state agency so they know it's coming. It has our name on it and the agency has to contract with us. And in the case of the program, they're delighted because now there is

money that they have available for more services and they're not spending their money out of the fund, which they do if we don't -- if we're not successful with this other. Now, the danger of all this is something I just found out this year and I'm not sure I would have been doing this all along if I had known what I know now. And that is that there is a rule in Florida that if the governor does veto you, the state agency cannot contract with you for that same service. And I did not know that we were putting ourselves on the line like that every time we got in front of the governor.

GEOFFREY LAUER: What would that mean for you? If for some reason one of your member project requests was vetoed it would put what at risk for the association?

ELYNOR KAZUK: For the new project it wouldn't matter. But for the $785,000, what has been happening for the past five years is that we have an arrangement with the Department of Health that if we don't get money, they will fund us. We work to get as much money as we can into their agency. That's the way it works. They've been funding us and we have our family support program going. But if the governor had vetoed it, he vetoed $300 million of these projects this year. It was really scary. We would not be able to receive our contract -- our usual contract with the state.

GEOFFREY LAUER: Very challenging for you.

ELYNOR KAZUK: It was very scary. And he did sign it. So now what we're doing is working with the Department of Health because it's in their budget and if they would claim

us and put us in their regular request for -- in their own budget, then we don't have to go through all this process. Most years these agencies don't. They just consider these turkeys something that they have to contend with that is a favorite project of a legislator and they do go ahead and they have to because our name is on it, they have to write a contract with us. So we started that way by twisting of arms and that kind of thing but over the years, it's been really a nice partnership that we've put together and now the Department of Health likes to see us coming. I don't think they realized, nor did we, how much danger we were putting ourselves in.

GEOFFREY LAUER: There is a question here if you could describe a little bit more. You said that you got lucky in getting the full funding and the question is, can she operationalize what lucky meant?

ELYNOR KAZUK: Over the five years that we've been working with this lobbyist we've gotten the $300,000. We've always asked for $785 and we end up it gets cut. I think because -- I'm not sure. This is behind is scenes stuff our lobbyist does. He knows who's who. He trades off influences and does all that kind of stuff. He, I think, knew the person who was the up and coming speaker of the house, this is the way I believe it goes, who backed our -- and sponsored our project and I believe the governor needs the support of that person. Because it was that person whose project it was, I believe, that had something to do with it not getting cut. And if you can get the chairs of these committees to buy into it, it can go through. It is so much behind the scenes you need someone who knows how this works and that's what we pay for.

GEOFFREY LAUER:  Thank you very much.

ELYNOR KAZUK:  I think there is a like process in every other state.  I asked about that and our lobbyist thinks that's true.  Call your legislator and find out how you can submit a proposal.

GEOFFREY LAUER:  A member project request.

ELYNOR KAZUK: A member project request.

GEOFFREY LAUER: The other thing I hear you saying is look at the fine print.  Make sure you're not compromising yourself.  With things you're already doing?

ELYNOR KAZUK: It's a great way to get new things happening.

GEOFFREY LAUER: Right, great.  Thank you.  Thank you very much.  All right.  Tom Gode, executive director of the Brain Injury Association of Minnesota.  It will be slide 10, please.  He'll talk with us a bit about their success in increasing the D.U.I.  reinstatement fines and what that has generated in Minnesota.  And Tom, if you could turn up your volume a little bit.

TOM GODE: Thanks, Geoff. We even rehearsed that one. First I have to start off with a couple of short notes. Florida and New Jersey were definitely our role model. We saw they had done it, been successful and there was no reason it couldn't work if Minnesota. They were sort of our motivating factor going here. We also had a history of working with actually hiring on staff a lobbyist, and found that that wasn't extremely successful for us. So we took a different approach than using lobbyists on this one. And went to a community organizer approach. A grass roots -- somebody who knew the people and could be taught the legislative process. And we were fortunate, we had a young woman on staff, she would start with us as an intern and doing basic outreach and she had the passion and was that naive enough to think everybody wanted to listen to what she talked about. We trained her as a lobbyist. There has to be a conscious decision within the organization. I heard Julie say the board put her at financial risk to bring on the lobbyist they brought on. I would say we did the same thing. We knew we were taking a significant financial risk.

When our board took the policy statement to say that the development of public policy was a core issue for us, it was equal to providing information and resources as support, as anything else, it was a core issue. And we needed to be able to allocate dollars and personnel in the same form and manner to change and influence public policy. That was significant change for us. We had always done public policy out of my hip pocket with the exception of the year we brought a lobbyist on staff. Like I say, we took very much a grass roots approach. We conducted what we call town hall meetings. Legislative home visits. In 50 legislative district before we even talked to a legislator about this. So when

we did meet with legislators, they knew that we were representing the 20 or 30 folks out of their home community that they had to see at church and the grocery store every day. And we got very warm receptions.

We also selected two very passionate authors and they weren't necessarily passion about brain injury but passionate about any bill they carried so they became passionate about brain injury for that session. They walked us through the process. They told us who we needed to see and off we went to see them. It was really kind of cool to have two seasoned legislators as your mentors going through the process and doing the same thing that, quite frankly, we would have paid a lobbyist to do for us as far as strategy. Before we even introduced legislation we had met with all the key state departments that we thought had an investment in this one. And quite frankly, the ones we had regular relationships with nodded and agreed with us but were very hesitant. They agreed to not oppose us but they couldn't support it for fear. What we were trying to do is expand the funding that funds our trauma registry. In a session where they were trying to find a billion dollar deficit solution they were afraid they could lose the trauma registry.

For the peripheral organizations for public safety and folks that we have some contact with but not the relationships that we do with health or Human Services, they literally laughed at us to think that anybody would propose new spending in a session where the governor had pledged no new taxes and they needed to find a billion dollars in cuts. They didn't support us but didn't oppose us. They just saw us as comic relief, I think. The nice thing about our bill was, it wasn't a tax, it was a fee, as several had said before. And we found

legislators didn't have a lot of hesitation putting a fee on to drunk drivers. I think we only hit one legislator who looked us straight in the face and said people in my district drink and people in my district drive. There is no public transportation and I can't vote for it. He got picked up for D.U.I. this summer. So by being -- coming through the fee and through the state brain injury and spinal cord fund it stays as a designated fee and stays outside the budgeting process so it stays a little more secure than most of the general allocation spending. We took an 18-month lead time to conduct our legislative home visits.

We had a goal to meet with at least 50 of the legislators and that was both party's leadership and the committee members of the committees we were going through. We managed to accomplish . That our goal was to recruit 1,000 citizen advocates. People who would respond when asked to respond. We didn't quite hit our 1,000 but we hit 650. And they did respond. We took a little different approach than several of the states that we've heard. We orchestrated our testimonies in front of committees and really pulled it down to myself and then one single parent. Our whole bill was based on the outcomes that our HRSA project had gotten through resource facilitation and the parent who came in to testify was the parent of a young son who hadn't come through resource facilitation. And it was an incredible testimony because it was everything you picture of a family that has had no support. And in the 12 months it took him from the time his son was injured to connect with us, you know, everything that could happen did happen. And it was very evident to see that being connected to resource facilitation at time of discharge would have eliminated a lot of family crisis.

It would have saved the state significant Medicaid dollars on state institutionalization. We went with one person to testify but we also had probably almost 700 people who told their stories to legislators in legislative home visits and one-on-one meetings at the capitol. Our load was equally split between staff and volunteers. Our community organizer and myself couldn't have done it without our volunteers and our volunteers couldn't have done it without our community organizers. We also did a public awareness campaign, a little different than New Mexico's approach. Our house and Senate, the powers controlled by our rural legislators and they don't read the big papers and during sessions they're not even seeing the news very often. But they are reading their local papers and so we really nailed local papers in key districts with letters to the editors from people who had brain injury and their family members and for about three weeks you couldn't pick up a small town local paper in those districts and not find a letter to the editor.

GEOFFREY LAUER: Thank you. Let me pass a couple questions on to you that are specific to Minnesota. Randy Evans asks with regards to the Minnesota trust fund, are there certain service models or types of services that are eligible for funding? And alternatively, are there some service models that are not funded? That is, residential care?

TOM GODE: All of our services for individuals are funded through Medicaid. Our trust fund only funds two things. It funds our trauma registry and it funds the contract that our health department put out to provide information and resources to families -- individuals

and families with brain injury which we translate into resource facilitation. It doesn't provide anything specific to an individual. It's all covered under our Medicaid waivers.

GEOFFREY LAUER: Thank you. All right. Last but absolutely not least in these giants, Barbara Geiger- Parker from the Brain Injury Association of New Jersey regarding what is going on in New Jersey.

BARBARA GEIGER-PARKER: Thank you for inviting us. I want to start out by saying how impressed I am with my colleagues around the nation and all the good work that staff and volunteers are doing to begin to put more resources behind the needs that so many people with brain injury have. Also before I get started I just wanted to offer a little bit of advice that has worked very successfully for us in New Jersey. We have never hired a contract lobbyist but we have had a number of people with significant lobbying experience as members of our board of trustees. So we get a lot of good advice and we don't have to pay any money for that good advice. That is, you know, if you have some relationships like that with some lobbyists in your own state, you might want to begin to groom them for some board participation.

New Jersey has had the T.B.I. Medicaid waiver in place for ten years. It started out as a model waiver and as of January of 2004 we had 250 slots funded but were approved for an additional 50 slots. We had not received -- the waiver had not received any additional funds for the past two budget years. And we had been working very diligently within administrators within the Department of Human Services where our -- where our TBI

waiver is to assure that in the budget for fiscal year 2005 that additional funding would be included for the next 50 slots. In January of 2004, there was a waiting list of more than 175 Medicaid-eligible people whose lives would have been much better if they were using the services available only through the Medicaid waiver. We were very impressed and excited after a conference call that I was able to participate on with our commissioner of Human Services.

The day before the budget was announced the commission of Human Services conducted a series of conference calls to let advocates know what was going to be in the budget. I was very excited because the commissioner did say that there would be funding for the next 50 slots for the waiver. So I thought well, that's good. We've done a lot of work within the department and we've been successful. It will be in the governor's budget. The very next morning I received a frantic phone call from one of our state government friends saying that the commissioner had misspoken. That there was not actually new money in the budget, but that the commissioner was sure he would be able to find the time.8 million that would be needed for the funding on the state side for these next 50 slots. That was good to hear, but legislatively our committee within the Brain Injury Association, our advocacy and Public Affairs Committee decided we wanted assurance the funds would be there and that we were going to take a legislative approach.

One of our board members was very highly effective in facilitating a meeting between our association and the aide to assemblyman Lou Greenwald. He's the chair of the general assembly budget committee. He's a key player in what gets funded and what does not.

The result of that meeting is that he agreed to put out legislation that would add the 50 slots to our TBI waiver which is a home and community-based waiver, a long-term care waiver. When we had the assembly bill introduced we needed to have an identical bill introduced in the New Jersey state Senate. We're fortunate that Tom Grady, who is the director of advocacy in public affairs for the association here in New Jersey, was able to briefly speak to our state Senate president, Richard Cody, about this initiative. And Tom would be happy at some point; I'm sure, to give you some more detail about that meeting.

But as a result of this meeting, the Senate president did agree to have two new state senators support an identical bill in the state Senate. He felt it was such a worthy bill that he wanted to give some visibility to two new members of his party. And we were very pleased that we wound up having identical bills in both houses. I would say that the main obstacle that the association encountered was actually a parent of someone with a brain injury. At a state committee meeting we testified and the father of a young woman with brain injury testified against the bill. He argued that our waiver was an unfair program because it didn't serve people with brain injury who had been injured before the age of 16. In New Jersey we have a Division of developmental disabilities for people with ongoing needs if the brain injury happened before the age of 22. This was designed to help people injured later in life. What the father failed to mention was that his daughter was receiving services from the waiver through the Division of developmental disabilities.

Of course, when he testified, the other problem that emerged was that there was no representative from the Department of Human Services at the hearing to address any of

the questions that this father was raising. They could have counter argued what this dad was saying. And so that became a bit of a wrinkle for us. We were able to, you know, get the bill passed out through that committee and also successful -- were successful in the Senate side, but the state was -- and is supposed to take a look at the eligibility requirements for the waiver. We also had some problems with this dad who began to contact reporters and was trying to have a media campaign that would have derailed a bill that is really out to help 50 other people. When the newspaper reporter contacted us, we were in contact with our state Department of Human Services, who then contacted the reporter and really set the reporter straight on the eligibility requirements for D.D.D. versus the eligibility requirements for the Medicaid waiver.

Therefore, there was no story. Grass roots players were very important to this endeavor. We had members of our brain injury community make calls and send emails to key lawmakers and especially those key lawmakers who were on the budget committee, which is where the bill began. It did not have to go through any of the other committees. We also were pretty effective lobbying the Department of human services earlier in the process and we got a call, actually, from someone within the department saying, you know, we get it, please stop having people call. And that's always kind of a good thing to hear. As I mentioned before, one of our board members, John, was extremely critical to the process. He actually works within the auto insurance industry. And has come to know the association and appreciates all the work that we do.

I think if he hadn't facilitated the initial meeting between our association and assemblyman Greenwald's office it might have been harder for us to have this bill introduced. As I also mentioned it was important for us to have had the opportunity to speak with the Senate president and the person who does our advocacy work here, Tom Grady, used to work in the assembly for several members of the assembly so he was able to persuade them to become supporters of this bill also. In terms of what is important to the success, I think it's really kind of not giving up, as you've heard from others, and being rather relentless. We knew that adding the opportunities for people to live in the community by having those additional slots through the TBI waiver wasn't only the humanitarian way to do things but also the best cost way to do it. I guess that's all that I have to say.

GEOFFREY LAUER: Appreciate everybody who has taken some time. If we can go to the next slide for a second while I do a little bit of wrap-up here. One of the things that folks should know is that there are an increasing number of dedicated funding streams and trust funds being developed around the country. And the slide that is on the screen right now is a snapshot shared by our colleagues from the National Association of state head injury administrators that shows which states right now have trust funds or dedicated funding streams. In terms of -- in terms of where to go for more information, we'll touch base on how to get more information about each of these states in a few minutes. I guess as we wrap up are there any other final comments that our presenters who are still with us, anybody want to touch base on what they think hasn't been touched on or a summary comment or two? I know the three of you are not ever shy.

All right. If we can go to the next slide with key points this will stimulate some activities. Here are some of the key points I anticipated coming out from today. That advocates often work better with ADVORATE support. The advocates in the trenches often work better when they have a person on the inside, a bureaucrat, if you will, in a state agency setting helping them understand the implications of legislation and how that legislation is going to affect that state agency, assuming state agencies are the fun else -- funnels for most of these monies. Those monies will move through one or more state agencies before they get to their final sources. So working with those folks to optimize that is helpful and also keeps them from being an obstacle. The relationship with champions or gate keepers can't be overestimated. Some are paid champions, for knows who hire lobbyist. As Barbara pointed out in New Jersey their champions are folks on their advisory councils or boards with extensive lobbying experience. Do you have any tips on how to hunt down one of these gems?

BARBARA GEIGER-PARKER: Well, you know, we have been working with a number of these folks, you know, on safety legislation. We have a longstanding relationship with the New Jersey hospital association. And also learned about a number of lobbyists through there. You're already working with people that, you know, that have a sophisticated understanding of the process and very well developed networks. You just need to kind of let them know all the good work that you're doing and, you know, bring them to your annual meeting. Bring them to your seminar. And you'll be surprised. A lot of people want to do good and, you know, working with brain injury associations with an easy way to do good.

GEOFFREY LAUER: There is a question here to those of you on the line who have had paid lobbyists, this is from Carolyn in Wisconsin. How would a state affiliate go about finding a lobbyist and what should they expect to have to pay on average in the Midwest region, say, for example, in Milwaukee? Tom or Ellie?

ELYNOR KAZUK: We found ours through board member connections.

TOM GODE: We advertised for ours.

GEOFFREY LAUER: In the paper?

Tom Gode: In the paper.

GEOFFREY LAUER: What kind of pay, what kind of remuneration.

ELYNOR KAZUK: We pay $800 a month since expenses for five years. We are -- $1800 a month. We're told he's planning on raising that now especially since he was so successful this year.

TOM GODE: You have a bargain going there. In Minnesota, again, if you're going to contract and you're not looking to hire, you can probably get by cheaper, but at least in

Minnesota, a good lobbyist or public policy director is going to run you somewhere between $40,000 and $60,000 a year.

GEOFFREY LAUER: I have to tell you, many of our state affiliates, their toes just curled as they heard that. Let me ask the next question. Where did you go, Tom and Ellie to get the unrestricted funds? Through fundraisers that you've done or money you had in the bank or did you just forfeit your salary for the year?

GEOFFREY LAUER: It's money we had in the bank.

TOM GODE: We spent everything we had. The other thing is, though, I mean, when we hired a community organizer versus a lobbyist because we wanted the grass roots component. The lobbyist tends not to work in the grass roots. And they're much, much cheaper. You'll get them for half the price of a lobbyist, as long as there is a good mentor to work them through the process they can be very effective.

ELYNOR KAZUK: What is the range that you paid? That was for a full time person.

TOM GODE: Full time person for a grass roots. Mine was 25 years old straight out of college with a lot of passion but I think at the time I really hate to say outloud what I was paying her because I wasn't paying her much.

GEOFFREY LAUER: How about a range?

TOM GODE: 24 to 28. Probably 20 to 28.

GEOFFREY LAUER: Thank you.

BARBARA GEIGER-PARKER: This is Barbara again. I guess I need to make it clear that we've not hired a contract lobbyist; we do have a public policy person on staff. And, you know, and that also is critically important. And that person's position, part of what he does is educate and we can pay for the education with grant funds. The lobbying part we have to raise privately.

GEOFFREY LAUER: And then I know that New Mexico, Miryam Miller and Montana had to leave the webcast early but on behalf of them because I've talked with them about these projects. Neither of those states hired a lobbyist or had anybody else other than their core staff and volunteers. As Stacy mentioned earlier, it was very much a volunteer effort. She indicate it shut down the office for a while. I think what she meant by that is that it consumed the office for a period of time when it came down to crunch. She was having to track to see whether the bills were submitted and whether they went to committee on a regular basis and trying to provide support to the volunteers. It is not to be underestimated. Once you're over the top with this the funding streams give you a few more degrees of freedom than you might otherwise have had. One other piece here to throw in relative to the New Mexico story or anybody else's story. The change often takes multiple years. The faces of brain injury campaign in New Mexico was an amazing effort.

It was a campaign that had full support of the House of Representatives, all of whose members signed on as co-sponsors and then at the end was vetoed by the governor. But there are -- there is a very strong grass roots advocacy movement that's coming back to the legislature again this year to make those changes. That is what stimulated my last point here. There is more than one way to skin a pepper. I thought a vegetarian metaphor. There are different ways to the end result. There is a balance of grass roots advocacy and kind of insider activity. And sometimes one or the other can pull it off. In most of the cases it's some kind of balance that shifts back and forth between the both. So that's just a point that has come up. If anybody else is out there during the webcast and has final questions, please submit them now because we'll move on to where to go for more information. Slide 14, please. There are two primary websites that I would direct you to for more information on state policy and systems change. The first is funded through the traumatic brain injury act which was an act created in Congress based on the advocacy efforts of many of us. Many advocates at the traumatic brain injury technical assistance center and that is located at www.tbitac.org. A section called the tool box and in there there are a number of articles and briefs regarding funding and systems change at state policy for brain injury. In addition the National Association of state head injury administrators, one of the collaborating organizations, NASHIA at NASHIA.org has a section on their website called resources and there is a large publication in there which is called, "a guide to state government brain injury policies, funding and services" which I think took about a year out of Susan Connor's life. It has maps, grids on which states have trust funds and it has more information about trust funds there, as well as www.diausa, our national website. There are links to these and other sites.

If we go to the next slide, please. Archived in this webcast are the contact information for Cheryl Spencer, Stacy Rye, Tom Gode and in addition if we can go to the next slide, for Julie, Miryam, Barbara and Ellie. Finally what I'll be doing is emailing to the network the contact information for these folks plus their bank account numbers in the next couple of days. I'll probably delete the last piece. There is one more question. Actually a comment here. It is coming in from none other than Susan Connors indicating to us that the guide to state policies is being updated this year so the information regarding trust funds will be current again soon. Any other comments from the presenters? Very good.

Next slide. I just would like to thank everybody. Thank again the Maternal and Child Health Bureau for their support. To thank the University of Illinois at Chicago and to thank my colleagues across the country. Tom, Ellie, Julie, Miryam, Barbara and Stacy for taking some time out of their busy day to share with us all some of these points. They'll be used valuably over the coming years for guidance on how to establish dedicated funding streams and trust funds for people with brain injuries. We'll wrap this up. Thank you. If you have additional questions my email and phone number is up on the final slide and brain injury association of America thanks you for your time.