

Duchatschek, Daryl
 1501 Elmwood Ave
 Oshkosh, WI 54901-2735

Home: (920) 232-8719

Email: DLDuke5491@aol.COM

Contact Date: 09/05/2003

Contact Type: E-mail

Summary: Tuber Sclerosis

Issue:

Position:

Description: Jennifer, looks like you have already dealt with this issue with this constituent.

-----Original Message-----

From: Daryl & Darcy Duchatschek [mailto:dduchatschek@new.rr.com]

Sent: Monday, September 01, 2003 9:37 AM

To: sen.roessler@legis.state.wi.us

Subject: Tuberous Sclerosis Awareness

Dear Honorable Carol Roessler,

As I watch TV this morning, I am watching the MDA tele-a-thon, Why can't we do something like this for Tuberous Sclerosis. I know we have miscellaneous concerts and what not in different states. I know the Julianne Moore is a advocap for TS and was on Good Morning America, but why can't we do the same for all effect persons with TS? If 1 out of every 6000 people in this world are effected with TS, shouldn't we have the same coverage and exposure? Now I am not against MDA or any other diseases they are just as devastation AS TS.

Do you have any idea what the ratio is for MDA or any other disease. If we are 1 out of 6000, I am sure we are right up there with all the rest? I may be just wasting time here but I believe that I am not.

Thank you for your time. Your response is requested in this matter.

Daryl Duchatschek
 1501 Elmwood Ave.
 Oshkosh, WI 54901

File: S:\DOCS\Intern\Bruce\Tuberous Sclerosis.doc

Status: Done

Closed Date: 10/30/2003

Assigned: Halbur, Jennifer

Owner: Christianson, Bruce

Note **Note Date:** 09/24/2003

Summary: BC sent letter

Contact Type:

Description:

File: S:\DOCS\Intern\Bruce\Tuberous Sclerosis.doc

Note **Note Date:** 09/29/2003

Summary: Daryl e-mailed back

Contact Type: E-mail

Description:

-----Original Message-----

From: Daryl & Darcy Duchatschek [mailto:dduchatschek@new.rr.com]

Contact Detail

Sent: Friday, September 26, 2003 4:18 PM
 To: Sen. Carol Roessler
 Subject: 2003 Senate Resolution 17

Dear Honorable Roessler,

I wish to express my deepest thank you for write to me in regards to the matter of awareness for Tuberos Sclerosis here in Wisconsin.

I can not thank you enough for co-sponsoring this bill, I believe that is what it is called if I am correct. Is there anything else I can do further to help with this. If so please let me know and I will do just that.

Sincerely,
 Daryl L Duchatschek

Note **Note Date:** 10/28/2003

Summary: Daryl emailed back

Contact Type: E-mail

Description: -----Original Message-----

From: DDUCHATSCHEK@new.rr.com [mailto:DDUCHATSCHEK@new.rr.com]
 Sent: Tuesday, October 28, 2003 4:31 AM
 To: Kari Carlson
 Cc: Sen. Carol Roessler
 Subject: Re: WI Resolution

Kari,

I am sending Sen. Roessler a copy of this message. I anticipate that she will write back to the both of us to let us know how the resolution is going.

Daryl

----- Original Message -----

From: "Kari Carlson" <kari.carlson@tsalliance.org>
 To: "Daryl Duchatschek" <DDUCHATSCHEK@new.rr.com>
 Sent: Monday, October 27, 2003 3:28 PM
 Subject: WI Resolution

> Daryl:
 >
 > How is your the resolution in the WI State Senate coming along? I let
 Mike
 > Coburn know. Thank you so much for this effort.
 >
 > I am off to Houston today and tomorrow but will be sending Senator
 Roessler
 > a thank you note on Friday. Wanted to let you know.
 >
 > kari
 >
 >

Note **Note Date:** 10/30/2003

Summary: JH called

Contact Type:

Description: I called Daryl to let him know that the tuberous sclerosis bill is still in the Senate Org Committee.

Duchatschek, Daryl
1501 Elmwood Ave
Oshkosh, WI 54901-2735

Home: (920) 232-8719

Email: DLDuke5491@aol.COM

Contact Date: 06/03/2003

Contact Type: E-mail

Summary: TSC - Tuberous Sclerosis

Issue:

Position:

Description: Daryl Duchatschek
1501 Elmwood Ave.
Oshkosh, WI 54901
----- Original Message -----
From: Roessler, Carol
To: Daryl & Darcy Duchatschek
Sent: Tuesday, June 03, 2003 10:01 AM
Subject: RE: TSC - Tuberous Sclerosis

Thank you for your email.
Due to the volume of emails I receive, I ask that all emails include a

home address. This will ensure that my constituents receive the highest

priority. Your assistance is greatly appreciated. I look forward to your

response.

Sincerely,

CAROL ROESSLER

State Senator

-----Original Message-----
From: Daryl & Darcy Duchatschek [mailto:ddjaduke@earthlink.net]
Sent: Tuesday, June 03, 2003 9:59 AM
To: russell_feingold@feingold.senate.gov; senator_kohl@kohl.senate.gov
Cc: Rep. Gregg Underheim; sen.roessler@legis.state.wi.us
Subject: TSC - Tuberous Sclerosis

Good Morning,

On today's Good Morning America. There was a story about something that I am deeply familiar with. The story was in regards to TSC (Tuberous Sclerosis Complex).

My reason for writing you today is simple. What legislation is currently going on or will be going on in regards to TSC. What can be done to make TSC more of an awareness.

Every day a child comes into this world with tuberous sclerosis (TS) and over two thirds of those children have had no prior family history of TS, as was the case with my family. TS can strike any family, at any time, without warning, and for no

Contact Detail

known reason. Sometimes it isn't even diagnosed until years later. I had never heard of tuberous sclerosis until I lost my kidney to tuberous sclerosis in April of 2001.

After I learned that I had tuberous sclerosis, I took my daughters Jennifer & Amanda to Children's Hospital in Milwaukee to be tested. Jennifer was diagnosed right away and Amanda a couple months later. We learned that they indeed had tuberous sclerosis too.

Tuberous Sclerosis is a devastating genetic disorder that causes the formation of tumors in vital organs such as the brain, heart, skin, kidney, eyes and lungs. There are behavioral issues as well. The tumors can cause serious health problems like epilepsy, autism, heart disease, mental retardation, kidney involvement, as is the case with Jennifer and myself, lung disease, and even death. Amanda's diagnoses affects mainly her skin.

I am asking your help to make TSC more recognized in the state of Wisconsin. WE NEED YOUR HELP !!! Thank you for your time. I look forward to hearing back from you.

Sincerely,
Daryl, Jennifer & Amanda Duchatschek
All Effect With TSC

Status: Done

Closed Date: 09/10/2003

Assigned: Halbur, Jennifer

Owner: Rothwell, Julie

Note **Note Date:** 06/12/2003

Summary: another email

Contact Type: E-mail

Description: Daryl Duchatschek
1501 Elmwood Ave.
Oshkosh, WI 54901

I am seeking your support. We need more funding. We need more awareness for TSC - Tuberous Sclerosis. Good Morning America did a wonderful job, nationally. Now we need our representatives here in the State of Wisconsin to do the same. No child, No Adult is safe until there is a cure for TS. I am seeking your immediate attention to all bills currently or in future sections. We need more clinics here in Wisconsin that deal with Tuberous Sclerosis.

Every day a child comes into this world with tuberous sclerosis (TS) and over two thirds of those children have had no prior family history of TS, as was the case with my family. TS can strike any family, at any time, without warning, and for no known reason. Sometimes it isn't even diagnosed until years later. I had never heard of tuberous sclerosis until I lost my kidney to tuberous sclerosis in April of 2001.

After I learned that I had tuberous sclerosis, I took my daughters Jennifer & Amanda to Children's Hospital in Milwaukee to be tested. Jennifer was diagnosed right away and Amanda a couple months later. We learned that they indeed had tuberous sclerosis too.

Tuberous Sclerosis is a devastating genetic disorder that causes the formation of tumors in vital organs such as the brain, heart, skin, kidney, eyes and lungs. There are behavioral issues as well. The tumors can cause serious health problems like epilepsy, autism, heart disease, mental retardation, kidney involvement, as is the case with Jennifer and myself, lung disease, and even death. Amanda's diagnoses affects mainly her skin.

Thank you for your time.

Note **Note Date:** 06/12/2003

Summary: Leg Council

Contact Type: E-mail

Description: -----Original Message-----

From: Rose, Laura
Sent: Tuesday, June 10, 2003 3:47 PM
To: Rothwell, Julie
Subject: RE: Tuberous Sclerosis

Hi Julie,

There is nothing pending in our legislature regarding tuberous sclerosis; nor is there anything in current law specifically relating to tuberous sclerosis.

There was a congressional resolution that was adopted by the 107th congress a couple of years ago. I will send over a copy of that - it might be used as a model for a Senate Joint Resolution. Do you think that is something Carol would want to spend time on? It would increase awareness if a resolution was introduced and a public hearing held. However, funding is another story. That would be hard to obtain on the state level at this point in time (funding for research, that is).

Please give me a call if you'd like to discuss this further, and I will send over the information I referred to above.

Laura

Laura Rose
Leg. Council
(608) 266-9791
laura.rose@legis.state.wi.us

-----Original Message-----

Note **Note Date:** 06/26/2003

Summary: Laura Rose

Contact Type: E-mail

Description: -----Original Message-----

From: Rothwell, Julie
Sent: Thursday, June 26, 2003 1:27 PM
To: Rose, Laura
Subject: Tuberous Sclerosis

Hi Laura,

I am writing about the Tuberous Sclerosis ideas that you proposed. Carol is interested in doing a Senate Joint Resolution to model the congressional resolution that was adopted by the 107th congress. So if you could please send over that information it would be greatly appreciated!!

Thank you!

Julie A. Rothwell
State Senator Carol Roessler's office

18th Senate District
1-888-736-8720
(608) 266-5300

Note **Note Date:** 07/28/2003

Summary: called Daryl

Contact Type: Phone Call

Description: JR called Daryl to let him know that Carol is doing a joint resolution.

SR 17

Bam - 23 co's

Hay 54 -

2 gallons

TB in Animal

heads too

~~already
made cow
in Canada~~

Schultz

TB in
Michigan

Came close to losing
TB free with cattle.

1 cow in N.W. had TB

came from Canada

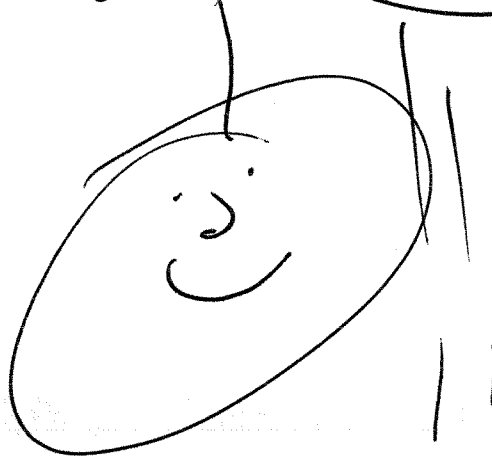
September 24, 2003

To: Carol

From: Jennifer

Re: Tuberous Sclerosis Senate Resolution3

Just FYI, Senator Lasee's office called to ask if you wanted your Tuberous Sclerosis bill to be referred to a your Committee or straight to Senate Organization. I told her to send it directly to Senate Organization.



WISCONSIN STATE SENATE



Carol Roessler
STATE SENATOR

September 24, 2003

Daryl Duchatschek
1501 Elmwood Ave.
Oshkosh WI, 54901-2735

Dear Daryl,

Thank you for your contact relating to Tuberous Sclerosis.

I understand fully that Tuberous Sclerosis is a serious disease that affects many people. In an effort to increase awareness of this disease I have introduced Senate Resolution 17. This resolution relates to increasing awareness, early and complete clinical testing, and improved health care services for detecting and treating tuberous sclerosis. I have attached a copy of Senate Resolution 17 for your review.

Thank you again for your contact. Please feel free to contact me with any further questions or concerns.

Sincerely,

A handwritten signature in black ink, appearing to read 'Carol', is written below the word 'Sincerely,'.

CAROL ROESSLER
State Senator
18th Senate District

CR:/jhS:\DOCS\intern\bruce\9-24-03 sb 17 tuberous Sclerosis.doc

Duchatschek, Daryl
 1501 Elmwood Ave
 Oshkosh, WI 54901-2735

Home: (920) 232-8719

Email: DLDuke5491@aol.COM

Contact Date: 09/05/2003

Contact Type: E-mail

Summary: Tuber Sclerosis

Issue:

Position:

Description: Jennifer, looks like you have already dealt with this issue with this constituent.

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From: Daryl & Darcy Duchatschek [mailto:dduchatschek@new.rr.com]
 Sent: Monday, September 01, 2003 9:37 AM
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 Subject: Tuberous Sclerosis Awareness

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Do you have any idea what the ratio is for MDA or any other disease. If we are 1 out of 6000, I am sure we are right up there with all the rest? I may be just wasting time here but I believe that I am not.

Thank you for your time. Your response is requested in this matter.

Daryl Duchatschek
 1501 Elmwood Ave.
 Oshkosh, WI 54901

File: S:\DOCS\Intern\Bruce\Tuberous Sclerosis.doc

Status: Done

Closed Date: 09/24/2003

Assigned: Halbur, Jennifer

Owner: Christianson, Bruce

Note **Note Date:** 09/24/2003

Summary: BC sent letter

Contact Type:

Description:

File: S:\DOCS\Intern\Bruce\Tuberous Sclerosis.doc

Halbur, Jennifer

From: on behalf of Sen.Roessler
To: *Legislative All Senate; *Legislative All Assembly
Subject: Senator Roessler Co-sponsorship LRB 3989/2 relating to providing awareness of tuberous sclerosis

TO: All Legislators
FROM: Senator Carol Roessler
DATE: August 25, 2003
RE: Co-sponsorship of LRB-2989/2, relating to: providing awareness of tuberous sclerosis by introducing a joint resolution.

Tuberous sclerosis affects at least 2 children every day and nearly 1,000,000 people worldwide are known to have tuberous sclerosis. Tuberous sclerosis affects all races and ethnic groups equally and is either an inherited autosomal disorder or by spontaneous mutation. Tuberous Sclerosis is the largest known genetic cause of epilepsy and is the second largest identifiable genetic cause of autism and frequently goes undiagnosed.

This resolution will call attention to tuberous sclerosis and will recognize the efforts of community and national organizations that promote awareness of the importance of early diagnosis.

If you have any questions or would like to co-sponsor the legislation, please contact my office at 266-5300 no later than **September 19th**.



FW: LRB-3163/2
(attached as re...

LKB 39812

WISCONSIN STATE SENATE

Tubercus Schoss

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3 (2) COWLES, Robert	6-0484	122 S.	Roger Frings, Jennifer Halbur, Cynthia, Boley
(8) DARLING, Alberta	6-5830	317 E.	Jessica Tormey, Thomas Petri, Tom O'Day, Rebecca Hogan Katherine Ford, David Volz
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(10) HARSDORF, Sheila	6-7745	131 S.	Jack Jablonski, Christian Schneider, Kimberly Tohm, Matt Woebke, Maya Ziv-el
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5 (33) KANAVAS, Ted	6-9174	20 S.	Bruce Pfaff, Marianne Foster, Michael Richards, Jeremy Shepherd
(11) KEDZIE, Neal	6-2635	313 S.	Dan Johnson, Matt Phillips, Heather Smith, Cory Bruce
(1) LASEE, Alan	6-3512	219 S.	Shari Lord, Kenlyn Harris, Allison Coakley
6 (24) LASSA, Julie	6-3123	3 S.	Jessica Kelly, Dan Kursevski
4 (28) LAZICH, Mary	6-5400	127 S.	Cathleen Connolly, Ann Marie Molitor, Thomas Van Ess, Wendi Zitske
(9) LEIBHAM, Joseph	6-2056	409 S.	Patrick Vander Sanden, Daniel Lindstedt, Brett Davis, Kathryn Prange
(32) MEYER, Mark	6-5490	109 S.	Grant Huber, Bryan Brooks, Ryan Natzke
(4) MOORE, Gwendolynne	6-5810	415 S.	Shirley Ellis, Leanne Bergstrom, Kelly Bablitch, Rachel Roller
(20) PANZER, Mary	6-7513	211 S.	Greg Hubbard, Tad Ottman, Rose Lemke, Lisa Davidson, Kelly Rindfleisch, Jennifer Esser
(7) PLALE, Jeff	6-7505	106 S.	Susie Schooff, Katy Venskus, Jeff Valenzuela
(5) REYNOLDS, Tom	6-2512	306 S.	Steve Krieser, Adam Peer, Les Wakefield, Nick Cekosh
(26) RISSER, Fred	6-1627	123 S.	Leslie Travis, Cindy Ashley, Sarah Briganti, Dianne Cieslewicz
(15) ROBSON, Judith	6-2253	5 S.	Kathleen Soderbloom, Kelley Flury, Justin Sargent
(18) ROESSLER, Carol	6-5300	8 S.	Karen Asbjornson, Sara Jermstad, Sara Seaquist, Todd Stuart
2 (17) SCHULTZ, Dale	6-0703	18 S.	Thomas Jackson, John O'Brien, Eileen O'Neill, Jonathan Klein
(21) STEPP, Cathy	6-1832	7 S.	Scott Manley, Pat Rasmussen, Jay Risch, Brian Pleva
(14) WELCH, Robert	6-0751	10 S.	Mary Ellen Boario, Christopher Newhouse, Bradley Boycks, Tricia Sieg, Amy Ferris
(22) WIRCH, Robert	7-8979	108 S.	Pat Erickson, Amber Meyer, Kelly Johnson
(23) ZIEN, David	6-7511	15 S.	Robert Seitz, Peter Hanson, John Hogan, Susan Marcott

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				www.legis.state.wi.us/		

DIRECT ALL SENATE CORRESPONDENCE TO: P. O. BOX 7882, MADISON, WI 53707-7882

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REPRESENTATIVE	ROOM	PHONE	REPRESENTATIVE	ROOM	PHONE
AINSWORTH, John (R-6)	309-North	6-3097	MONTGOMERY, Phil (R-4)	129-West	6-5840
ALBERS, Sheryl (R-50)	3-North	6-8531	MORRIS, Johnnie (D-11)	118-North	6-3756
BALOW, Larry (D-68)	126-North	6-9172	MUSSER, Tony (R-92)	11-West	6-7461
BERCEAU, Terese (D-76)	208-North	6-3784	NASS, Stephen (R-31)	12-West	6-5715
BIES, Garey (R-1)	125-West	6-5350	NISCHKE, Ann (R-97)	8-North	6-8580
BLACK, Spencer (D-77)	214-North	6-7521	OLSEN, Luther (R-41)	9-West	6-8077
BOYLE, Frank (D-73)	221-North	6-0640	OTT, Alvin (R-3)	318-North	6-5831
COGGS, G. Spencer (D-17)	210-North	6-5580	OWENS, Carol (R-53)	315-North	7-7990
COLON, Pedro (D-8)	5-North	7-7669	PETROWSKI, Jerry (R-86)	4-West	6-1182
CULLEN, David (D-13)	216-North	7-9836	PETTIS, Mark (R-28)	20-North	7-2365
FITZGERALD, Jeff (R-39)	308-North	6-2540	PLALE, Jeffrey (D-21)	107-North	6-0610
FOTI, Steven (R-38)	215-West	6-2401	PLOUFF, Joe (D-29)	306-West	6-7683
FREESE, Stephen (R-51)	115-West	6-7502	POCAN, Mark (D-78)	322-West	6-8570
FRISKE, Donald (R-35)	312-North	6-7694	POPE-ROBERTS, Sony (D-79)	420-North	6-3520
GARD, John (R-89)	211-West	6-3387	POWERS, Michael (R-80)	310-North	6-1192
GIELOW, Curt (R-23)	316-North	6-0486	RHOADES, Kitty (R-30)	321-East	6-1526
GOTTLIEB, Mark (R-60)	304-North	7-2369	RICHARDS, Jon (D-19)	6-North	6-0650
GRONEMUS, Barbara (D-91)	114-North	6-7015	RILEY, Antonio (D-18)	209-North	6-0645
GROTHMAN, Glenn (R-58)	15-North	4-8486	SCHNEIDER, Marlin (D-72)	204-North	6-0215
GUNDERSON, Scott (R-83)	7-West	6-3363	SCHOOFF, Dan (D-45)	220-North	6-9967
GUNDRUM, Mark (R-84)	19-North	7-5158	SERATTI, Lorraine (R-36)	18-North	6-3780
HAAHN, Eugene (R-47)	15-West	6-3404	SHERMAN, Gary (D-74)	320-North	6-7690
HEBL, Tom (D-46)	304-West	6-7678	SHILLING, Jennifer (D-95)	120-North	6-5780
HINES, J.A. (R-42)	10-West	6-7746	SINICKI, Christine (D-20)	321-West	6-8588
HUBER, Gregory (D-85)	218-North	6-0654	STASKUNAS, Tony (D-15)	124-North	6-0620
HUBLER, Mary (D-75)	119-North	6-2519	STEINBRINK, John (D-65)	307-West	6-0455
HUEBSCH, Michael (R-94)	304-East	6-0631	STONE, Jeff (R-82)	320-East	6-8590
HUNDERTMARK, Jean (R-40)	13-West	6-3794	SUDER, Scott (R-69)	21-North	7-0280
JENSEN, Scott (R-98)	123-West	4-6970	TOWNS, Debi (R-43)	302-North	6-9650
JESKEWITZ, Suzanne (R-24)	314-North	6-3796	TOWNSEND, John (R-52)	22-West	6-3156
JOHNSRUD, DuWayne (R-96)	323-North	6-3534	TRAVIS, David (D-81)	223-North	6-5340
KAUFERT, Dean (R-55)	308-East	6-5719	TURNER, Robert (D-61)	219-North	6-0731
KERKMAN, Samatha (R-66)	109-West	6-2530	UNDERHEIM, Gregg (R-54)	11-North	6-2254
KESTELL, Steve (R-27)	17-West	6-8530	VAN AKKEREN, Terry (D-26)	409-North	6-0656
KRAWCZYK, Judy (R-88)	9-North	6-0485	VAN ROY, Karl (R-90)	8-West	6-0616
KREIBICH, Robin (R-93)	107-West	6-0660	VRAKAS, Daniel (R-33)	119-West	6-3007
KREUSER, James (D-64)	201-West	6-5504	VRUWINK, Amy Sue (D-70)	412-North	6-8366
KRUG, Shirley (D-12)	212-North	6-5813	VUKMIR, Leah (R-14)	307-North	6-9180
KRUSICK, Margaret (D-7)	128-North	6-1733	WARD, David (R-37)	324-East	6-3790
LADWIG, Bonnie (R-63)	113-West	6-9171	WASSERMAN, Sheldon (D-22)	111-North	6-7671
LASEE, Frank (R-2)	105-West	6-9870	WEBER, Becky (R-5)	115-West	6-2418
LASSA, Julie (D-71)	122-North	7-9649	WIECKERT, Steve (R-57)	16-West	6-3070
LEHMAN, John (D-62)	303-West	6-0634	WILLIAMS, Annette (D-10)	113-North	6-0960
LEHMAN, Michael (R-99)	103-West	7-2367	WILLIAMS, Mary (R-87)	18-West	6-7506
LeMAHIEU, Daniel (R-59)	17-North	6-9175	WOOD, Jeffrey (R-67)	7-North	6-1194
LOEFFELHOLZ, Gabe (R-49)	317-North	6-1170	WOOD, Wayne (D-44)	104-North	6-7503
LOTHIAN, Thomas (R-32)	306-North	6-1190	YOUNG, Leon (D-16)	109-North	6-3786
McCORMICK, Terri (R-56)	127-West	6-7500	ZEPNICK, Josh (D-9)	418-North	6-1707
MEYER, Dan (R-34)	306-East	6-7141	ZIEGELBAUER, Bob (D-25)	207-North	6-0315
MILLER, Mark (D-48)	112-North	6-5342			

CHIEF CLERK, Patrick Fuller	208-RJC	6-5811	Supplies / Document Room	121-RJC	6-2400
Asst. Chief Clerk, Vacant	208-RJC	7-4355	Quick Copy Center	17 SF	6-5591
Adm. Asst/Maint.Request (Linda)	208-RJC	6-7674	Leg. Audit Bureau	22 E. Mifflin	6-2818
General Info/Supplies (Laura)	208-RJC	6-1501	Leg. Council	401-Main	6-1304
Records (Ken)	208-RJC	6-2406	Leg. Fiscal Bureau	301-Main	6-3847
Bulletins (Jody)	208-RJC	6-2545	Legislative Hotline	121-RJC	6-9960
Journals (Kay)	208-RJC	6-5550	(Toll-free number)	800-362-9472	
Per Diem/Roll Calls (Doris)	208-RJC	4-8588	Hearing Impaired	800-228-2115	
Assembly Printing/Travel (Mary)	208-RJC	6-1108	Leg. Post Office	B25-West	6-5837
Assembly Office Accts. (Julanne)	208-RJC	6-3826	LRB-Reference Section	2nd-Hamilton	6-0341
Telephones/Voicemail (Lonni)	208-RJC	6-2006	LRB-Bill Drafting	5th-Hamilton	6-3561
Chief Clerk Fax Number		6-5617	LTSB Technical Support	400 SF	7-9528
Legislative Human Resources	301-RJC	4-8471	Call Forwarding to SGT	411-West	6-3044
Rick Skindrud, Sgt-at-Arms	411-West	7-9808	Capitol Buildings and Grounds	B20-SE	6-1485
Sergeant's Staff	411-West	6-1503	CAPITOL POLICE DEPT.	B2-North	6-7700

Graphic Artist-Lee Riedesel	B-41-West	4-8395	Photographer-Brent Nicastro	B-7-West	1-9476
Graphic Artist-DeAnna Williams	B-41-West	6-8603	Photographer-Jay Salvo	B-14-West	7-0897

Leg. Website: www.legis.state.wi.us
 Mailing: PO Box 8952(Reps A-L) PO Box 8953(Reps M-Z) Madison, WI 53708 E-Mail: Rep.(insert last name)@legis.state.wi.us
 HEARING ROOMS: NHR(2ND FL) 4-8317...417 NORTH (GAR) 4-8318...225 NW 6-3454...300 NE 6-7646...328 NW 6-2403...400 NE 6-2848
 412 E 6-7632...415 NW 6-2411

* 9-22-03 Call all highlighted Reps to let them know that CR is moving forward with a Senate Resolution. - not JT.

107th Congress Points on Tuberous Sclerosis

***Senator Roessler would like a Senate Assembly Resolution**

Whereas at least two children born each day will be affected with tuberous sclerosis;

Whereas nearly one million people worldwide are known to have tuberous sclerosis;

Whereas tuberous sclerosis affects all races and ethnic groups equally;

Whereas tuberous sclerosis is caused by either an inherited autosomal disorder or by a spontaneous genetic mutation;

Whereas when tuberous sclerosis is genetically transmitted as an autosomal dominant disorder, a child with a parent with the gene will have a 50-percent chance of inheriting the disease;

Whereas two-thirds of the cases of tuberous sclerosis are believed to be a result of spontaneous mutation, although the cause of such mutations is a mystery;

Whereas diagnosis takes an average of 90 days with consultation of at least three specialists;

Whereas tuberous sclerosis is the largest known genetic cause of epilepsy;

Whereas tuberous sclerosis is now the second largest identifiable genetic cause of autism;

Whereas tuberous sclerosis frequently goes undiagnosed because of the obscurity of the disease and the mild form the symptoms may take; and

Whereas the Congress as an institution, and Members of Congress as individual, are in unique positions to help raise public awareness about the need for increased funding for research, detection, and treatment of tuberous sclerosis and to support the fight against tuberous sclerosis.;

Whereas all Americans should take an active role in the fight against tuberous sclerosis by all means available to them, including early and complete clinical testing and investigating family histories;

Whereas Wisconsin has the responsibility to endeavor to raise awareness about the importance of the early detection of, and proper treatment for, tuberous sclerosis;

The role played by national and community organizations and health care providers in promoting awareness of the importance of early diagnosis, testing, and ongoing screening should be recognized and applauded;

Whereas as a state and nation we need to continue to consider ways to improve access to, and the quality of, health care services for detecting and treating tuberous sclerosis.

Rothwell, Julie

Tuberous Sclerosis

From: Jermstad, Sara
Sent: Thursday, June 05, 2003 2:51 PM
To: Rothwell, Julie
Subject: FW: New Forward Contact Ownership and Assignment

You're already working on a case similar to this, right?

Sara Jermstad
Office of Senator Carol Roessler
Sara.Jermstad@legis.state.wi.us
(608)266-5300 / 888-736-8720

Tuberous Sclerosis Alliance
1-800-225-6872

International

1 month

-----Original Message-----

From: Rohrer, Daniel
Sent: Thursday, June 05, 2003 2:45 PM
To: Jermstad, Sara; Jermstad, Sara
Subject: New Forward Contact Ownership and Assignment

Constituent: Daryl Duchatschek (23330)
1501 Elmwood Ave
Oshkosh, WI 54901-2735

Home: 920-232-8719

Email: DLDDuke5491@aol.COM

Owner: Jermstad, Sara
Assigned: Jermstad, Sara
Summary: TSC

Issue:
Position:
Status: Pending
Contact Type: E-mail
Description: Daryl Duchatschek
1501 Elmwood Ave.
Oshkosh, WI 54901

I am seeking your support. We need more funding. We need more awareness for TSC - Tuberous Sclerosis. Good Morning America did a wonderful job, nationally. Now we need our representatives here in the State of Wisconsin to do the same. No child, No Adult is safe until there is a cure for TS. I am seeking your immediate attention to all bills currently or in future sections. We need more clinics here in Wisconsin that deal with Tuberous Sclerosis.

Every day a child comes into this world with tuberous sclerosis (TS) and over two thirds of those children have had no prior family history of TS, as was the case with my family. TS can strike any family, at any time, without warning, and for no known reason. Sometimes it isn't even diagnosed until years later. I had never heard of tuberous sclerosis until I lost my kidney to tuberous sclerosis in April of 2001.

After I learned that I had tuberous sclerosis, I took my daughters Jennifer & Amanda to Children's Hospital in Milwaukee to be tested. Jennifer was diagnosed right away and Amanda a couple months later. We learned that they indeed had tuberous sclerosis too.

Neurofibromatosis is a devastating genetic disorder that causes the formation of tumors in vital organs such as the brain, heart, skin, kidney, eyes and lungs. There are behavioral issues as well. The tumors can cause serious health problems like epilepsy, autism, heart disease, mental retardation, kidney involvement, as is the case with Jennifer and myself, lung disease, and even death. Amanda's diagnosis affects mainly her skin.

Thank you for your time.

Rothwell, Julie

From: Rose, Laura
Sent: Tuesday, June 10, 2003 3:47 PM
To: Rothwell, Julie
Subject: RE: Tuberous Sclerosis

Saw

OK

Hi Julie,

There is nothing pending in our legislature regarding tuberous sclerosis; nor is there anything in current law specifically relating to tuberous sclerosis.

There was a congressional resolution that was adopted by the 107th congress a couple of years ago. I will send over a copy of that - it might be used as a model for a Senate Joint Resolution. Do you think that is something Carol would want to spend time on? It would increase awareness if a resolution was introduced and a public hearing held. However, funding is another story. That would be hard to obtain on the state level at this point in time (funding for research, that is).

Please give me a call if you'd like to discuss this further, and I will send over the information I referred to above.

Laura

Laura Rose
Leg. Council
(608) 266-9791
laura.rose@legis.state.wi.us

No to Public Hearing.

-----Original Message-----

From: Rothwell, Julie
Sent: Monday, June 09, 2003 11:34 AM
To: Rose, Laura
Subject: Tuberous Sclerosis

Hi Laura,

I have a constituent issue and I really don't know where to begin, or if your even the right person to talk to, but I thought I would give it a stab. So here it goes, We have a constituent who wrote us regarding Tuberous Sclerosis. They are writing for more funding and more awareness. I was wondering if there are any current laws or upcoming legislation dealing with this issue.
Thank you!

Julie Rothwell
Office of Senator Carol Roessler
266-5300

Rothwell, Julie

Subject: FW: Tuberous Sclerosis

-----Original Message-----

From: Rothwell, Julie
Sent: Thursday, June 26, 2003 1:27 PM
To: Rose, Laura
Subject: Tuberous Sclerosis

Hi Laura,

I am writing about the Tuberous Sclerosis ideas that you proposed. Carol is interested in doing a Senate Joint Resolution to model the congressional resolution that was adopted by the 107th congress. So if you could please send over that information it would be greatly appreciated!!

Thank you!

Julie A. Rothwell
State Senator Carol Roessler's office
18th Senate District
1-888-736-8720
(608) 266-5300

Rothwell, Julie

From: Jermstad, Sara
Sent: Tuesday, June 03, 2003 10:37 AM
To: Rothwell, Julie
Subject: FW: New Forward Contact Ownership and Assignment

Please look into this. See if feds are doing anything, too, maybe.

Thank you!

Sara Jermstad
Office of Senator Carol Roessler
Sara.Jermstad@legis.state.wi.us
(608)266-5300 / 888-736-8720

-----Original Message-----

From: Rohrer, Daniel
Sent: Tuesday, June 03, 2003 10:16 AM
To: Jermstad, Sara; Jermstad, Sara
Subject: New Forward Contact Ownership and Assignment

Constituent: Daryl Duchatschek (23330)
1501 Elmwood Ave
Oshkosh, WI 54901-2735

Home: 920-232-8719

Email: DLDuke5491@aol.COM

Owner: Jermstad, Sara
Assigned: Jermstad, Sara
Summary: TSC - Tuberous Sclerosis

Issue:
Position:
Status: Pending
Contact Type: E-mail
Description: Daryl Duchatschek
1501 Elmwood Ave.
Oshkosh, WI 54901

----- Original Message -----

From: Roessler, Carol
To: Daryl & Darcy Duchatschek
Sent: Tuesday, June 03, 2003 10:01 AM
Subject: RE: TSC - Tuberous Sclerosis

Thank you for your email.
Due to the volume of emails I receive, I ask that all emails include a
home address. This will ensure that my constituents receive the highest
priority. Your assistance is greatly appreciated. I look forward to your
response.

Sincerely,

AROL ROESSLER

State Senator

-----Original Message-----

From: Daryl & Darcy Duchatschek [mailto:ddjaduke@earthlink.net]

Sent: Tuesday, June 03, 2003 9:59 AM

To: russell_feingold@feingold.senate.gov; senator_kohl@kohl.senate.gov

Cc: Rep. Gregg Underheim; sen.roessler@legis.state.wi.us

Subject: TSC - Tuberous Sclerosis

Good Morning,

On today's Good Morning America. There was a story about something that I am deeply familiar with. The story was in regards to TSC (Tuberous Sclerosis Complex).

My reason for writing you today is simple. What legislation is currently going on or will be going on in regards to TSC. What can be done to make TSC more of an awareness.

Every day a child comes into this world with tuberous sclerosis (TS) and over two thirds of those children have had no prior family history of TS, as was the case with my family. TS can strike any family, at any time, without warning, and for no known reason. Sometimes it isn't even diagnosed until years later. I had never heard of tuberous sclerosis until I lost my kidney to tuberous sclerosis in April of 2001.

After I learned that I had tuberous sclerosis, I took my daughters Jennifer & Amanda to Children's Hospital in Milwaukee to be tested. Jennifer was diagnosed right away and Amanda a couple months later. We learned that they indeed had tuberous sclerosis too.

Tuberous Sclerosis is a devastating genetic disorder that causes the formation of tumors in vital organs such as the brain, heart, skin, kidney, eyes and lungs. There are behavioral issues as well. The tumors can cause serious health problems like epilepsy, autism, heart disease, mental retardation, kidney involvement, as is the case with Jennifer and myself, lung disease, and even death. Amanda's diagnoses affects mainly her skin.

I am asking your help to make TSC more recognized in the state of Wisconsin. WE NEED YOUR HELP !!! Thank you for your time. I look forward to hearing back from you.

Sincerely,

Daryl, Jennifer & Amanda Duchatschek

All Effect With TSC

Rothwell, Julie

From: Rose, Laura
Sent: Tuesday, June 10, 2003 3:47 PM
To: Rothwell, Julie
Subject: RE: Tuberous Sclerosis

Hi Julie,

There is nothing pending in our legislature regarding tuberous sclerosis; nor is there anything in current law specifically relating to tuberous sclerosis.

There was a congressional resolution that was adopted by the 107th congress a couple of years ago. I will send over a copy of that - it might be used as a model for a Senate Joint Resolution. Do you think that is something Carol would want to spend time on? It would increase awareness if a resolution was introduced and a public hearing held. However, funding is another story. That would be hard to obtain on the state level at this point in time (funding for research, that is).

Please give me a call if you'd like to discuss this further, and I will send over the information I referred to above.

Laura

Laura Rose
Leg. Council
(608) 266-9791
laura.rose@legis.state.wi.us

-----Original Message-----

From: Rothwell, Julie
Sent: Monday, June 09, 2003 11:34 AM
To: Rose, Laura
Subject: Tuberous Sclerosis

Hi Laura,

I have a constituent issue and I really don't know where to begin, or if your even the right person to talk to, but I thought I would give it a stab. So here it goes, We have a constituent who wrote us regarding Tuberous Sclerosis. They are writing for more funding and more awareness. I was wondering if there are any current laws or upcoming legislation dealing with this issue.
Thank you!

Julie Rothwell
Office of Senator Carol Roessler
266-5300

Senate / ~~Asses~~ ST.

107th Congress Points on Tuberous Sclerosis

Concurrent Resolution

~~Expressing the sense of the Congress regarding tuberous sclerosis~~

Whereas at least two children born each day will be affected with tuberous sclerosis;

Whereas nearly one million people worldwide are known to have tuberous sclerosis;

Whereas tuberous sclerosis affects all races and ethnic groups equally;

Whereas tuberous sclerosis is caused by either an inherited autosomal disorder or by a spontaneous genetic mutation;

Whereas when tuberous sclerosis is genetically transmitted as an autosomal dominant disorder, a child with a parent with the gene will have a 50-percent chance of inheriting the disease;

Whereas two-thirds of the cases of tuberous sclerosis are believed to be a result of spontaneous mutation, although the cause of such mutations is a mystery;

Whereas diagnosis takes an average of 90 days with consultation of at least three specialists;

Whereas tuberous sclerosis is the largest known genetic cause of epilepsy;

Whereas tuberous sclerosis is now the second largest identifiable genetic cause of autism;

Whereas tuberous sclerosis frequently goes undiagnosed because of the obscurity of the disease and the mild form the symptoms may take; and

Whereas the Congress as an institution, and Members of Congress as individual, are in unique positions to help raise public awareness about the need for increased funding for research, detection, and treatment of tuberous sclerosis and to support the fight against tuberous sclerosis.

Whereas two-thirds of the cases of tuberous sclerosis are believed to be a result of spontaneous mutation, although the cause of such mutations is a mystery;

Whereas diagnosis takes an average of 90 days with consultation of at least three specialists;

Whereas tuberous sclerosis frequently goes undiagnosed because of the obscurity of the disease and the mild form the symptoms may take; and

Whereas the Congress as an institution, and Members of Congress as individuals, are in unique positions to help raise public awareness about the need for increased funding for research, detection, and treatment of tuberous sclerosis and to support the fight against tuberous sclerosis: Now, therefore, be it

Resolved by the House of Representatives (the Senate concurring), That it is the sense of the Congress that--

① where as

① all Americans should take an active role in the fight against tuberous sclerosis by all means available to them, including early and complete clinical testing and investigating family histories;

③ ② the role played by national and community organizations and health care providers in promoting awareness of the importance of early diagnosis, testing, and ongoing screening should be recognized and applauded;

(3) the Federal Government has a responsibility to--

② where as we

(A) endeavor to raise awareness about the importance of the early detection of, and proper treatment for, tuberous sclerosis;

(B) increase funding for research so that the causes of, and improved treatment for, tuberous sclerosis may be discovered; and

④ where as a state to ... nation we need cont

(C) continue to consider ways to improve access to, and the quality of, health care services for detecting and treating tuberous sclerosis; and

(4) the Director of the National Institutes of Health should take a leadership role in the fight against tuberous sclerosis by acting with appropriate offices within the National Institutes of Health to provide to the Congress a five-year research plan for tuberous sclerosis.

107th CONGRESS

1st Session

No. 107-181e

107th Congress Points on Tuberous Sclerosis

Concurrent Resolution

Expressing the sense of the Congress regarding tuberous sclerosis

Whereas at least two children born each day will be affected with tuberous sclerosis;

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Whereas the Congress as an institution, and Members of Congress as individual, are in unique positions to help raise public awareness about the need for increased funding for research, detection, and treatment of tuberous sclerosis and to support the fight against tuberous sclerosis.