

2011 Conference Attendee Directory

First	Last	City	State	Zip	Country	Phone	Email	Relation	Rett Child	Age	Mutation
Paula	Agins	Westerly	RI	02891		401-596-1858	pmagins@gmail.com	Parent	Sarah Agins	25	
Kathleen	Ahern	Haveville	MA			978-761-7877	teeckidz@gmail.com	Professional: Teacher	Kelly Schoener	17	
Cordelia	Albanese	Las Vegas	NV	89147		702-489-9105	albo145@yahoo.com	Parent	Michelle Albanese	8	r306c
Don	Albanese	Bloomfield	NJ	07003		973-338-6269	dalbanes@westex.org	Grandparent	Michelle Albanese	8	r306c
Linda	Albanese	Bloomfield	NJ	07003		973-338-6269	dalbanes@westex.org	Grandparent	Michelle Albanese	8	r306c
Charis	Alejo	Iligan City		09200	Philippines	63-221-4926	yetalajo@hotmail.com	Parent	Loris Alexa Alejo	6	
Billy	Babiarz	Wheaton	IL	60187		847-331-3905	jpcorrado31@yahoo.com	Parent	Cameron Babiarz	2	
Jackie	Babiarz	Wheaton	IL	60187		847-331-3905	jpcorrado31@yahoo.com	Parent	Cameron Babiarz	2	
Stephen	Bajardi	New York	NY				sbajardi@rettsyndrome.org	Staff/Speaker			
Jim	Bathie	Waukesha	WI	53186		414-828-2271	jim.bathie@metso.com	Parent	Keira Bathie	3	R133C
Katie	Bathie	Waukesha	WI	53186		414-828-2271	katie_frazier@hotmail.com	Parent	Keira Bathie	3	R133C
Barbara	Berlin	Potomac	MD	20854		301-299-7380	bbbpxx@aol.com	Grandparent	Violet Berlin	3	R168X
Laura	Berlin	Bethesda	MD	20816		301-320-4122	lauraberlin@verizon.net	Parent	Violet Berlin	3	R168X
Noah	Berlin	Bethesda	MD	20816		301-320-4122	noah.berlin@gmail.com	Parent	Violet Berlin	3	R168X
Eryn	Biddiscombe	Sherwood Park		T8A 2X5		780-717-3581	Eryn_B@shaw.ca	Professional: Interventionist	NA	NA	
Marla	Black	Mount Juliet	TN	37122		615-414-0137	mabsbb1@gmail.com	Parent	Sydney Breanne Black	18	
Sumathi	Blaji						bnambi@yahoo.com		Srinidhi Balaji	6	R106W
Mitch	Bleske	Madison	MA	39110		601-707-5152	mbleske@trustmark.com	Parent	Riley Bleske	5	c.391dupA
Erin	Bleske	Madison	MS	39110		601-707-5152	erinbleske@hotmail.com	Parent	Riley Bleske	5	c.391dupA
David	Boutin	Williamstown	VT	05680			shelv13@myfairpoint.net	Parent	Payton Boutin	4	

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Michele	Boutin	Williamstown	VT	05679			shelv13@myfairpoint.net	Parent	Payton Boutin	3	
Dena	Brevich	Walpole	MA				DenaBrev@verizon.net	Professional: teacher			
Steven	Brookins	Chittenango	NY	13037		315-687-9337	tbrookins08@aol.com	Parent	Alexandria Brookins	7	Large Deletions of exons 3 and 5
Tabitha	Brookins	Chittenango	NY	13037		315-687-9337	tbrookins08@aol.com	Parent	Alexandria Brookins	7	Large Deletions of exons 3 and 4
Jennifer	Brown	Oak Forest	IL	60451		708-535-9132	jenniferbrown79@aol.com	Parent	Lily Brown	2	R255X
Jonathan	Brown	Oak Forest	IL	60452		708-535-9133	jenniferbrown79@aol.com	Parent	Lily Brown	2	R255X
Douglas	Brunner	Cross Plains	WI	53528		608-798-0077	dpbrune@tds.net	Parent	Jessica Brunner	12	
Paula	Brunner	Cross Plains	WI	53529		608-798-0078	dpbrune@tds.net	Parent	Jessica Brunner	12	
Bonnie	Budd	Leominster	MA	01453		978-466-3923	budd0806@gmail.com	Parent	Sabrina Budd	6	atypical rett syndrome with preserved speech
Lisa	Byrne	Cincinnati	OH	45244		513-474-1290	dbyrne@cinci.rr.com	Parent	Alison Byrne	15	R306C
Cheryl	Campbell	Arlington	MA	02474		781-643-5168	tj8934@me.com	Parent	Jana Campbell	16	
Frances	Carlisle	San Bernardino	CA	92407		951-818-5071	fjc63057@aol.com	Grandparent	Rylie Whiting	8	
Kay	Carson	Lafayette	LA	70598		337-406-0123	kakacarson@aol.com	Grandparent	Reagan Conroy	3	
Mike	Carson	Lafayette	LA	70598		337-406-0123	mike@mikecarsonconstruction.com	Grandparent	Reagan Conroy	3	
Gwen	Casey	Valley Village	CA	91607		818-679-6868	gwencasey@hotmail.com	Parent	Joanna Casey	28	
Maureen	Charamella	Springfield	PA	19064		215-879-5365	maureen.charamella@yahoo.com	Parent	Deirdre Charamella	26	
Mark	Charamella	Springfield	PA	19064		215-879-5365	maureen.charamella@yahoo.com	Parent	Deirdre Charamella	26	
Vineta	Chen	West Lafayette	IN	47906			vineta@gmail.com	Parents	Julie Chen	31	
Alejandra	Ciancaglini	Buenos Aires		01426			alejandra_8171@yahoo.com.ar	Parent	Mariana Ciancaglini	27	
Florencia	Cirigliano	Buenos Aires		01426			fcirigliano@redcoachusa.com	Sibling	Mariana Ciancaglini	27	

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Kevin	Coloton	Chevy Chase	MD	20815			colotonfamily@gmail.com	Parent	Catalina Coloton	4	Q227fs
Dawn	Conroy	Cedar Creek	TX	78612			dawn@scp-tx.com	Parent	Raegan Haley Conroy	3	r168x
Wes	Conroy	Cedar Creek	TX	78612			wes@scp-tx.com	Parent	Raegan Haley Conroy	3	r168x
Anne	Costello	Concord	CA	94521		925-672-6245	acpc@astound.net	Grandparent	Camilla Johnson	4	R306C
Lou Ann	Counihan	Bloomfield Hills	MI	48302			lcouniha@umich.edu	Parent	Megan Counihan	25	
Terry	Counihan	Bloomfield Hills	MI	48302			terrycounihan@att.net	Parent	Megan Counihan	25	
Leslie	Courtney	Worcester	MA	01610		508-757-9952		Parent	Lily Courtney	8	
Erin	Craig	Palo Alto	CA	94301		650-321-5741	erinishuman@gmail.com	Parent	Kim Dvorak	21	
Angie	Crandall	Jacksonville	NC	28540		910-581-4420	acrandall@ec.rr.com	Parent	Sydney Jolan Crandall	3	R133C
Rob	Crandall	Jacksonville	NC	28540		910-581-4420	acrandall@ec.rr.com	Parent	Sydney Jolan Crandall	3	R133C
Jaymie	Crosser	Aurora	NE	68818		308-379-6471	jaymie.crosser@live.com	Parent	Jessalyn Fillingner	3	
Kathy	Crowther	Sanford	CO	81151			w_crowther@hotmail.com	Parent	Mandy Lou Crowther	22	
Warren	Crowther	Sanford	CO	81151			w_crowther@hotmail.com	Parent	Mandy Lou Crowther	22	
Carole	Cushman	Dublin	OH	43016		614-356-3728	carolecushman@columbus.rr.com	Parent	Erin Cushman	8	
Douglas	Cushmasn	Dublin	OH	43016		614-940-5732	dugcushman@columbus.rr.com	Parent	Erin Cushman	8	R133C
Sara	Davidson	Watertown	MA	02472		339-221-0368	davidssc@bc.edu	Professional: Special Edu.			
Stacy	Daye	Canton	GA	30114		678-644-0607	sdaye@att.net	Parent	La'Mara Daye	22 months	P.R168X
Kate	DeBettencourt	Lunenburg	MA				owenberu@aol.com	PCA/Family Friend	Kendra O'Brien	7	
Keith	Detweiler	Hansville	WA	98340		360-509-2109	kjdet44@aol.com	Parent	Lily Caroline Detweiler	3	R306C
Lily	Detweiler	Hansville	WA	98340		360-509-2109	lika5605@hotmail.com	Parent	Lily Caroline Detweiler	3	R306C

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Lisa	Detweiler	Hansville	WA	98340		360-509-2109	lika5605@hotmail.com	Parent	Lily Caroline Detweiler	3	R306C
Pam	Diener	Bethesda	MD				psd23@georgetown.edu	Sibling	Jalie Diener	46	
Candra	Dion	White River Jct.	VT	05001		603-398-3148	dioncandra@hotmail.com	Parent	Caitlyn Dion	6	
Marcia	Ditt Cury	Jundiai		13207491		55-113-379-1311	mdcury@legatto.com.br	Parent	Isabela Ditt Cury	11	p.P152R
Kathy	Dryer	Aurora	NE	68818		402-69-1223	kdyer@esu9.org	Professional: Educator	NA	NA	NA
David	Ducharme	Richmond	RI	02875		401-213-0222	david@thinkoutside.co	Uncle	Sorel Kolendrianos	5	
Dorothy	Ehrenberg	Cosh octon	OH	43812		740-622-8211	dkehrenberg@sbcglobal.net	Granparent	Erin Cushman	8	R133C
Jennifer	Endres	Yarmouth Port	MA				jendres@rettsyndrome.org	Parent/Staff	Jillian Endres	8	
Colleen	English	Scotts Valley	CA	95066		831-461-1064	colleen748@yahoo.com	Parent	Claire English	5	R133P
Jane	Erickson	Haysville	KS	67060		316-529-3698	info@armbraces.com	Grandparent	Jayden Huber	13	
Karen	Esteban	Quantico	MD	21856		410-572-2718	rambusticated@gmail.com	Parent	Zoila Butler	5	deletion exon 4
Dylan Lawrence	Fallon	Danvers	MA	01923		978-621-6337	fal10falcon@aol.com	Sibling	Jordan Fallon	20	C-T 763 R255X
Joe	Fanska	Lakeville	MN	55044		932-435-5780	jfanska@yahoo.com	Parent	Eve Fanska	4	
Shawna	Fanska	Lakeville	MN	55044		952-435-5780	shawnafanska@yahoo.com	Parent	Eve Fanska	4	
Pat	Fay	Glastonbury	CT	06033		860-652-8252	rsmama1@cox.net	Parent	Meghan Fay	18	
Ed	Fennel							Parent			
Barbara	Ferrarotti	Torrington	CT	06790		860-489-9435	barbara9600@sbcglobal.net	Parent	Carla Ferrarotti	40	
Robert	Ferrarotti	Torrington	CT	06790		860-489-9435	barbara9600@sbcglobal.net	Parent	Carla Ferrarotti	40	
Jeremy	Fillinger	Aurora	NE	68818		402-631-6564	jaymie.crosser@live.com	Parent	Jessalyn Fillinger	3	
Joanne	Fleming	Chestnut Hill	MA	02467			jmfflem729@yahoo.com	Professional: School Nurse			

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Adel	Forsythe	Valley View	TX	76272		940-765-9223	adelforsythe@me.com	Parent	Kathryn Forsythe	8	
Billy	Forsythe	Valley View	TX	76272		940-765-9223	adelforsythe@me.com	Parent	Kathryn Forsythe	8	
Kay	Fortenberry	Manassas	VA	20112		703-590-6209	forten@comcast.net	Parent	Paige Fortenberry	22	R294X
Erica	Frazier	Statham	GA	30666			fraziere@clarke.k12.ga.us	Parent	Anna Kate Frazier	2	
April	Frazier	Statham	GA	30666			fraziere@clarke.k12.ga.us	Parent	Anna Kate Frazier	2	
Nicole	Friel	North Andover	MA				nicole@thefriels.com	Parent	Abigail Friel	7	
Tom	Friel	North Andover	MA				tfriel@onecommunications.com	Parent	Abigail Friel	7	
Clifford	Fry	College Station	TX	77840		979-696-0866	jcfry@suddenlink.net	Parent	Ashley Fry	31	Y141X
Judy	Fry	College Station	TX	77841		979-696-0867	jcfry@suddenlink.net	Parent	Ashley Fry	31	Y141X
Miriam	Ganz	New York	NY	10004		212-613-8198	miriamganz@yahoo.com	Aunt	Rina Miriam Pavlov	7	c.753delC, p.P251fs288X
Rebecca	Garner	Glenfield	NY	13343		315-348-2623	rgarner@southlewis.org	School Psychologist	Jocelyn Strigle	7	
Pat	George	Concord	CA	94518		925-984-0076	patgeorge1789@yahoo.com	Grandparent	Katie Nues	8	
Gonzalez	Gianni	Miami	FL	33184		305-781-2696	gggtony@msn.com	Parent	Gianni Gonzalez	5	
Joy	Gibbs	Bournes Village	St. George	BB19051	Barbados	246-437-9180	sweettips@hotmail.com	Parent	Jolaina Waldron	4	
Irene	Gladstone	Needham	MA	02494		781-444-8164	iglad@rcn.com	Parent	Erika Gladstone	32	C316T
Linda	Goldman	Needham	MA	02494		781-449-1898	lgoldman@comcast.net	Parent	Jessica Goldman	31	
Jenni	Grammer	Cincinnati	OH				jgrammer@rettsyndrome.org	Staff			
Dewayne	Gregory	Fort Smith	AR	72901		479-782-4555	lisa_darisse@yahoo.com	Parent	Emily Sipes	3	
Lisa	Gregory	Fort Smith	AR	72903		479-459-8341	lisa_darisse@yahoo.com	Parent	Emily Sipes	3	
Mary Joyce	Griffin	Cincinnati	OH				mgriffin@rettsyndrome.org	Staff			

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Katie	Guernsey	Bangor	ME	04401		207-745-0379	kgguernsey@aol.com	Parent	Abby Guernsey	8	R168x
Vicky	Guess	Rancho Cordova	CA	95670		916-638-7614	vlguess@gmail.com	Parent	Isabella Guess	4	R133H
Betsy	Hall	Penfield	NY	14526		585-381-9962	EHALL18@rochester.rr.com	Parent	Grace Hall	7	deletion of axions 3 and 4
John	Hall	Penfield	NY	14526		585-381-9962	EHALL18@rochester.rr.com	Parent	Grace Hall	7	deletion of axions 3 and 4
Sheryl	Hand	Prattville	AL	36067		334-201-6718	handsheryl@gmail.com	Parent	Angela Hand	19	
Lisa	Hayden	Cincinnati	OH				lhayden@rettsyndrome.org	Staff			
Amie	Heinzerth	Rockford	IL	61107		815-282-2842	rsrebar@aol.com	Grandparent	Emily Enos	7	
Ronald	Heinzerth	Rockford	IL	61114		815-282-1439	rsrebar@aol.com	Grandparent	Emily Enos	7	
Sharon	Heinzerth	Rockford	IL	61114		815-282-1439	rsrebar@aol.com	Grandparent	Emily Enos	7	
Kris	Herlitz	Larchmont	NY	10538			kris@herlitz.com	Parent	Daisy Herlitz	11	
Violaine	Herlitz	Larchmont	NY	10538			vgherlitz@aol.com	Parent	Daisy Herlitz	11	
Tony	Horton	New York	NY				thorton@rettsyndrome.org	Staff/Speaker			
Tonya	Hudson	Columbia	SC	29229		803-661-8152	tdhudson70@live.com	Parent	Mayree Littlejohn	6	
Diane	Hughson	Townsend	MA	01469		978-597-6581	dboneh@comcast.net	Parent	Jennifer Hughson	32	
Shirley	Hurlburt	Liverpool	NY	13088		315-314-6858	kksmom@twcny.rr.com	Parent	Kaila Maclaury		
Lisa	Hymers	East Meredith	NY	13757		607-278-5929	leemh@live.com	Parent	Lyndsay Hymers	18	
Christine	Jackson	Chardon	OH	44024		330-348-1188	cpandkj1@windstream.net	Parent	Elyse Jackson	5	Deletion
Kyle	Jackson	Chardon	OH	44024		330-348-1188	cpandkj1@windstream.net	Parent	Elyse Jackson	5	Deletion
Corey	Jackson	Cambridge	OH	43725		740-630-3170	axjax76@yahoo.com	Uncle	Elyse Jackson	6	
Shannon	Jackson	Cambridge	OH	43725		740-630-3170	axjax76@yahoo.com	Aunt	Elyse Jackson	6	

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Amanda	Jacobs	Van Buren	OH	45889		419-257-3055	jacobs91@frontier.com	Parent	Paige Jacobs	18	
Lori	Johnson	Las Vegas	NV	89144		702-463-846	dirklori@gmail.com	Parent	Camilla Johnson	4	R306C
Tricia	Johnson	Dennis	MA	02638		508-385-4193	johnsonsindennis@comcast.net	Professional: Teacher			
Martha	Jones	Glenfield	NY	13343		315-348-2623	mjones@southlewis.org	Professional: Principal	Jocelyn Strigle	7	
Jane	Joyce	Hingham	MA	02043			jane.joyce@comcast.net	Parent	Caroline Joyce	11	
Kanakavalli	Kannan	Fremont	CA	94555			kkanaks@yahoo.com	Parent	Janani Anand	4	T158M
Bonnie	Keck	Allentown	PA	18103		610-439-0515	bondon@ptd.net	Parent	Lyndie Keck	24	T158M
Don	Keck	Allentown	PA	18103		610-439-0515	bondon@ptd.net	Parent	Lyndie Keck	24	T158M
Jim	Keller	New York	NY				jkeller@rettsyndrome.org	Staff			
Sharon	Kelly	Glenfield	NY	13343		315-348-2623	skelly@southlewis.org	Professional: Special Edu.	Jocelyn Strigle	7	
Cathy	Kenngott	Akron	OH	44312		330-990-2230	cather3@uakron.edu	Parent	Sarah Kenngott	16	
David	Keselica	Reno	NV	89511			dkeselica@charter.net	Parent	Annie Keselica	22	
Victoria	Kirihara	Honolulu	HI	96825		808-383-5948	vkirihara@gmail.com	Parent	Michelle Kirihara	34	
Sydney	Kleine	Sherwood Park		T8A 0S7		780-278-5955	sydneyarlette@hotmail.com	Caregiver	Joanne Picard	12	
Chris	Kolendrianos	Goleta	CA	93117		805-570-5275	ckgraphics@cox.net	Parent	Sorel Kolendrianos	5	R255X
Melissa	Kuhlman	Cincinnati	OH				mkuhlman@rettsyndrome.org	Staff			
Steven	Langsdale	Minnetonka	MN	55305		952-544-1503	slangsdale@mohawkmoving.com	Friend	Sara Brinkhaus	12	
Rich	Laufer	Bowie	MD	20715		301-805-1793	laufhome@comcast.net	Parent	Katie Laufer	14	
Sherry	Laufer	Bowie	MD	20715		301-805-1793	laufhome@comcast.net	Parent	Katie Laufer	14	
Maren	Layton	Mountain View	CA	94043		801-592-2332	marejl@gmail.com	Parent	Leah Layton	4	P101R, P113R

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Jodie	Lee	Petal	MS	39465		601-520-5703	ben.lee1331@gmail.com	Parent	Mary Claire Lee	11	
Susan	Lee	Pelham	AL	35124		205-444-4696	slee@shelbyed.k12.al.us	Parent	Alyssa Lee	3	
Walt	Lee	Pelham	AL	35124		205-444-4696	slee@shelbyed.k12.al.us	Parent	Alyssa Lee	3	
Christine	Leiter	Carrollton	TX	75007		214-755-3221	thejleiters@verizon.net	Parent	Melanie Nicholle Leiter	30	
Jeffrey	Leiter	Carrollton	TX	75007		214-755-3221	jlleiter@verizon.net	Parent	Melanie Nicholle Leiter	30	
Kristin	Leopoldino	old Saybrook	CT	06475		860-399-7900	sxct06426@asol.com	Parent	Avery Leopoldin	3	
Carole	Levesque	Wells	ME	04090		207-467-9120	clevesque11@maine.rr.com	Grandparent	Abigail Friel	7	
Linda	Lindbeck	Greenville	NC	27834			lindbeck@embarqmail.com	Parent	Britt Lindbeck	14	
Angele	Lockhart	Saskatoon		S7L 7W9		306-931-4826	dlockhart@shaw.ca	Grandparent	Avery Norris	2	
Douglas	Lockhart	Saskatoon		S7L 7W9		306-931-4826	dlockhart@shaw.ca	Grandparent	Avery Norris	2	
Liz	Luzadder	Lake Worth	FL	33467		561-433-8696	lizluz@bellsouth.net	Parent	Marissa Luzadder	10	
Candice	Masters	Medfield	MA	02052		617-686-0210	candicemasters@gmail.com	Speech Therapist	Caitlin McCarthy	8	R294X
Pam	Mayo Roman	Subdivision, Lipa City	Batangas	04216	Phillipines	6-343-312-1526	myhunnypots@yahoo.com	Parent	Julia Roman	9	
Jeanne	Mazzaferro	Rochester	NY	14612		585-227-6935	jmazzaferro@rochester.rr.com	Grandparent	Sophie Rector	4	T158M
Vince	Mazzaferro	Rochester	NY	14612		585-227-6935	jmazzaferro@rochester.rr.com	Grandparent	Sophie Rector	4	T158M
Dwight	McBee	Barnegat	NJ	08005		609-312-7263	dmcbee@atlanticare.org	Parent	Siena Grace McBee	3	R270X
Karen	McBee	Barnegat	NJ	08005		609-312-7263	karen_ravaioli@yahoo.com	Parent	Siena Grace McBee	3	R270X
Susan	McCarthy	Walpole	MA	02081		508-668-6198	mccarthysusie@yahoo.com	Parent	Caitlin McCarthy	8	R294X
Dave	McCool	O'Fallon	MO	63368		314-610-5651	dmccool@watlow.com	Parent	Ellie McCool	13	
Mickie	McCool	O'Fallon	MO	63368		314-610-5651	mickmccool@charter.net	Parent/Speaker	Ellie McCool	13	

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Ann	McDermott	Louisville	KY	40204		502-930-3334	amcdermott@insightbb.com	Parent	Abby McDermott	5	R168X
Wendy	McEwen	Saskatoon		S7J 2W7		306-343-0131	jimcewendy@sasktel.net	Parent	Elizabeth McEwen	11	MeCP2b
Linda	McInnis	Bradford	MA	01835		978-372-3459	Jlmcinn4@comcast.net	Parent	Katilyn McInnis	9	Deletion Exon 3,4, and SCAD Mitochondrial
Gerry	McTernan	Needham	MA	02492		617-759-4051	gmcternan@rmmlaw.com	Parent	Lori McTernan	19	
Maria	McTernan	Needham	MA	02492		617-759-4051	mtmcternan@gmail.com	Parent	Lori McTernan	19	
Karen	Medlin	Marlboro	NJ			732-740-0449	3grlsmom@optonline.net	Parent	Taylor Medlin	18	
Steven	Medlin	Marlboro	NJ			732-740-0449	3grlsmom@optonline.net	Parent	Taylor Medlin	18	
Cathy	Merrill	Charlton	MA	01507			smerri@charter.net	Parent	Melinda Merrill	18	IV3 3C->G
Matt	Mevis	Green Bay	WI				mmevis@sbcglobal.net	Parent	Kira Mevis	5	R255x
Patty	Mevis	Green Bay	WI				mmevis@sbcglobal.net	Parent	Kira Mevis	5	R255x
Pati	Mitchell	Arlington	TX	76010			myjesigirl@yahoo.com	Grandparent/Guardian	Alison Rinkenberger	7	
Catriona	Moore	London		SE15 5NY			catrionamoore@hotmail.co.uk	Parent	Amy Reyes	3	R168X
Jan	Myles		NY	14051		716-689-0953		Parent	Mary Myles	50	
Alexandra	Nevins-Nordland	Yonkers	NY	10704		914-423-6909	anevins@optonline.net	Parent	Siobhan	8	
John	Nordland	Yonkers	NY	10704		914-423-6909	jrnord@optonline.net	Parent	Siobhan	8	
Kris	Norris	La Ronge		S0J 1L0		306-425-3029	mellockhart@hotmail.com	Parent	Avery Norris	2	
Melanie	Norris	La Ronge		S0J 1L0		306-425-3029	mellockhart@hotmail.com	Parent	Avery Norris	2	
Jean-Francois	Novel	Geneva		01203		0041-79-302-41-11	jf.novel@orange.fr	Grandparent	Leev Novel	3	
Paige	Nues	Danville	CA				pnues@rettsyndrome.org	Parent/Staff	Katie Nues	8	
Jesse	Nues	Danville	CA				pnues@rettsyndrome.org	Parent	Katie Nues	8	

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First	Last	City	State	Zip	Country	Phone	Email	Relation	Rett Child	Age	Mutation
Deberah	Patterson	Houston	TX	77089		281-997-0450	ThePattersonFamily5@gmail.com	Parent	Caitlyn Patterson	6	R168X
Patrick	Patterson	Houston	TX	77089		281-997-0450	ThePattersonFamily5@gmail.com	Parent	Caitlyn Patterson	6	R168X
Karon	Paulhus	Monson	MA	01057		413-267-4320	kpaulhus@charter.net	Parent	Emma Paulhus	11	T158
Aliza	Pavlov	Beitar	Illit	90500	Israel	4-972-72-230-4559	csp@shearim.com	Parent	Rina Miriam Pavlov	7	c.753delC, p.P251fs288X
Jospeh	Peden	Centerville	PA	16404			julesrtr_1@hotmail.com	Parent	Jorja Peden	3	R133C
Julie	Peden	Centerville	PA	16404			julesrtr_1@hotmail.com	Parent	Jorja Peden	3	R133C
Heather	Perricone	Arlington	TX				hperrico@aisd.net	Professional: Teacher	Alison Rinkenberger	7	
Paulette	Pfannenstiel	Sacramento	CA	95829		916-682-2729		Parent	Pamela Pfannenstiel	25	R270x
Dominique	Pichard	Chevy Chase	MD	20815			colotonfamily@gmail.com	Parent	Catalina Coloton	4	Q227fs
Anna	Pike	South Plympton	South Australia	05038	Australia	882937632	annamosas@hotmail.com	Parent	Abby Pike	2	
Anita	Poulton	Goodlettsville	TN	37072		615-859-0080	a.poulton@comcast.net	Parent	Sonora Lynne Poulton	12	
Brent	Poulton	Goodlettsville	TN	37072		615-859-0080	a.poulton@comcast.net	Grandparent	Sonora Lynne Poulton	12	
Nancy	Prendergast	Chevy Chase	MD	20815			nanpren@gmail.com	Grandparent	Catalina Coloton	4	
Molly	Priest	Rockford	IL	61107		614-327-4579	rsrebar@aol.com	Aunt	Emily Enos	7	
Emilie	Rabke	Glen Allen	VA	23060		804-762-8668	emilierabke@gmail.com	Parent	Anna Cate Rabke	9	C Terminal Deletion
Jessica	Rector	Rochester	NY	14612		585-720-0793	jrector1@rochester.rr.com	Parent	Sophie Rector	4	T158M
Jonathan	Rector	Rochester	NY	14612		585-720-0793	jrector1@rochester.rr.com	Parent	Sophie Rector	4	T158M
Katie	Roach	Hanover	NH	03755			katie.roach@hanovernorwichschools.org	Professional: Educator	NA	NA	NA
Erica	Robertson	Pleasant Hill	CA	94523		925-212-3733	ericabrobertson@gmail.com	Parent	Avery Robertson	4	C917_939del23
Joy	Rosen	Ellijay	GA	30540		678-357-1578	joy.rosen@hotmail.com	Grandparent	Caroline King	4	MeCP2

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First	Last	City	State	Zip	Country	Phone	Email	Relation	Rett Child	Age	Mutation
Diane	Ross	Schaumburg	IL	60193		847-885-7790	diross62@aol.com	Parent/Speaker	Lindsey Ross	24	294
Mary Ann	Sabo	Edgewater	MD				msabo@cwtsatotravel.com	Parent	Katie Sabo	21	tm158
Arlen	Schechtman	Concord	CA	94518		925-984-0076	patgeorge1789@yahoo.com	Grandparent	Katie Nues	8	
Kathleen	Schoener	Southborough	MA	01772			kathy.schoener@gmail.com	Parent	Kelly Schoener	17	
Katharine	Schrader	Ellsworth	ME	04605		207-266-2541	klschrader@rocketmail.com	Professional: Teacher			
Kenna	Seiler	The Woodlands	TX	77381		936-321-3870	kennaseiler@me.com	Parent	Rachael Seiler	6	R270X
Jenny	Shah	Bethesda	MD	20816			jenshah1@gmail.com	Parent	Sejal Shah	5	T158M
Rajat	Shah	Bethesda	MD	20816			rajat.shah77@yahoo.com	Parent	Sejal Shah	5	T158M
Deirdre	Shipstead	Agoura Hills	CA				shipstead@mindspring.com	Aunt	Kim Dvorak	21	
Jennifer	Shober	Westfield	NJ	07090		908-232-1318	jenshober@hotmail.com	Parent	Ysabel Shober	5	R168X
Jim	Small	Chandler	AZ				jsmall@parkerfinch.com	Parent	Sophia Small	6	
Jennifer	Smith	Covington	GA	30014		678-446-7492	faith1_2@msn.com	Parent	Josie Coburn	3	
Angie	Snyder	Nemaha	IA	50567		712-660-8089	naeesnyder@yahoo.com	Parent	Ellie Snyder	4	
Deborah	Stevens	Chelburne Falls	MA	01370		431-625-2322	dhsesq84@verizon.net	Parent	Carly Stevens	19	
James	Strigle	Constableville	NY	13325		315-397-2234	james100@frontiernet.net	Parent	Jocelyn Strigle	7	R306C
Jill	Strigle	Constableville	NY	13325		315-397-2234	james100@frontiernet.net	Parent	Jocelyn Strigle	7	R306C
Alana	Sullivan	Rochester	NY	14617		585-266-2405	ajhsullivan@gmail.com	Parent	Rachel Sullivan	6	r294X
Scott	Sullivan	Rochester	NY	14617		585-266-2405	ajhsullivan@gmail.com	Parent	Rachel Sullivan	6	r294X
Zoe	Sullivan	Rochester	NY	14617		585-266-2405	ajhsullivan@gmail.com	Sibling	Rachel Sullivan	6	
Renee	Suprenant	Pepperell	MA	01463		978-424-6779	soupeplus3@aol.com	Parent	Kendra Suprenant	7	R16X

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Evie Lynn	Swan	Reno	NV	89511		775-852-3059	evielynn@charter.net	Parent	Anne Keselica	22	
Eleonora	Tamasne	San Jose	CA	95128			eleonora.tamasne@gmail.com	Speaker			
Erica	Tempesta	North Reading	MA	01864		978-729-2982	eric_tempesta@yahoo.com	Parent	Juliana & Ava Tempesta	6	C1135_1142 deletion
Laura	Tempesta	North Reading	MA	01864		978-729-2982	eric_tempesta@yahoo.com	Parent	Juliana & Ava Tempesta	6	C1135_1142 deletion
Keira	Terrasson	Tomball	TX	77377		713-828-6752	keirat@comcast.net	Parent	Grace Terrasson	11	R168X
Gladys	Thomson	Flanders	NJ				gthomson@optonline.net	Parent	Keri Ann Thomson	24	
Laura	Thonnesen	Jefferson	NY	12093		607-652-3786	laurasgoldens@gmail.com	Friend & Professional	Lyndsay Hymers	18	
Angela	Traxler	Belle Plaine	MN	56011		952-378-3740	angietraxler@gmail.com	Parent	Madeline Belling	6	
Olga	Tsilevich	Royal Palm Beach	FL	33411		917-589-8089	olgamt3@aol.com	Behavior Analyst			
Edith	Turner	Matthews	VA	23109		757-344-5388	eturner@mathews.K12.va.us	Parent	Brittany Perrin-Turner	20	
Jill	Twigg	Pepperell	MA	01463		978-925-9587	munkhgt@yahoo.com	Parent	Olivia Twigg	3	
Rosalind	Vargo	Syrcause	NY	13203			RoV@twcny.rr.com	Parent	Ro Vargo	31	C763T
Patricia	Watson	Calgary	Alberta	T3G 4T6	CANADA	403-239-9478	mdwatson@shaw.ca	Parent	Laura Watson	25	R168X
Sandy	Whiting	San Berdino	CA	92404		909-886-0999	glazind@aol.com	Parent	Rylie Whiting	7	
Dennis	Whiting	San Berdino	CA	92404		909-886-0999	glazind@aol.com	Parent	Rylie Whiting	7	
Nakisha	Whittington	Vacherie	LA	70090		225-265-7624	kemiasobby1@yahoo.com	Sibling	Takemia Whittington		
Kevin	Wrenn	Haverhill	MA	01832			pmwrenn@yahoo.com	Parent	Julie Wrenn	10	
Penny	Wrenn	Haverhill	MA	01832			pmwrenn@yahoo.com	Parent	Julie Wrenn	10	
Maggie	Wurm	Wilbraham	MA	01095		413-279-1207	momtorettangel@yahoo.com	Parent/ Speaker	Madasyn Wurm	10	
Brian	Wurm	Springfield	MA	01109		413-279-1207	momtorettangel@yahoo.com	Parent	Madasyn Wurm	10	

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Janan	Zimmerman	Kalamazoo	MI	49048		269-388-9815	zimmermanj@comstockps.org	Professional: Educator			