

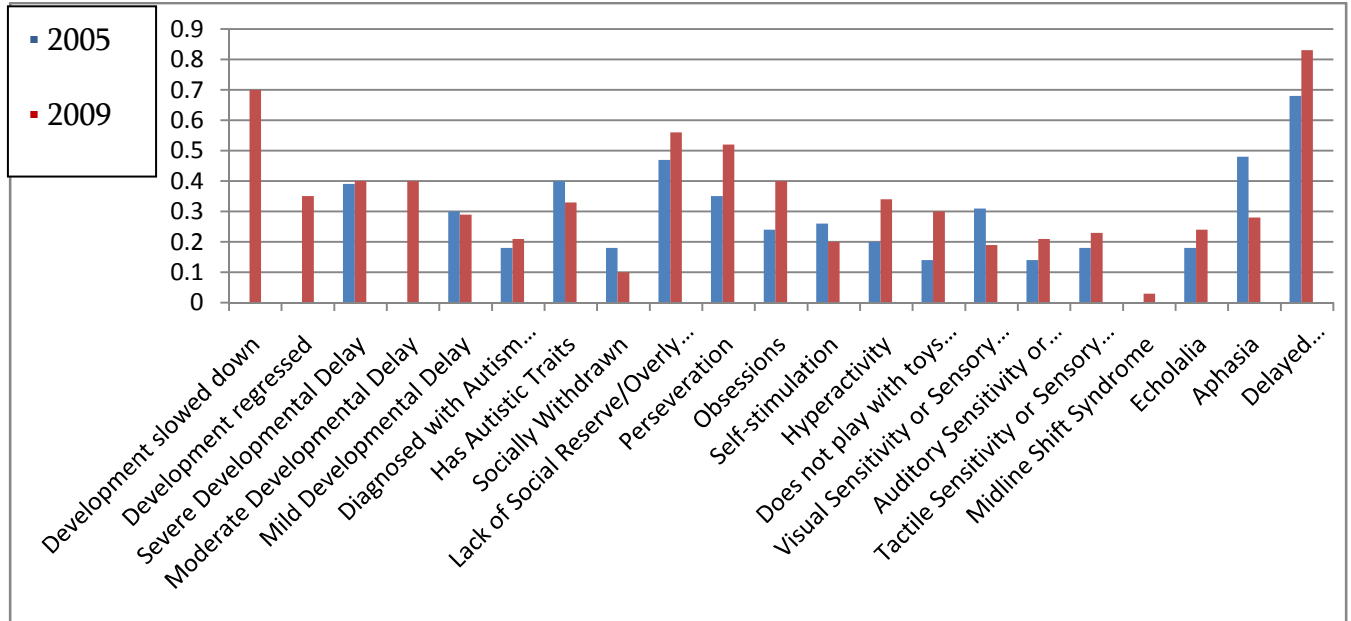
International Workshop on Dravet Syndrome: Severe Myoclonic Epilepsy of Infancy- 30 Years Later
Verona, Italy
October 4-6, 2009

Expanding the Clinical Spectrum: Updated Data on Comorbidities in Dravet Syndrome

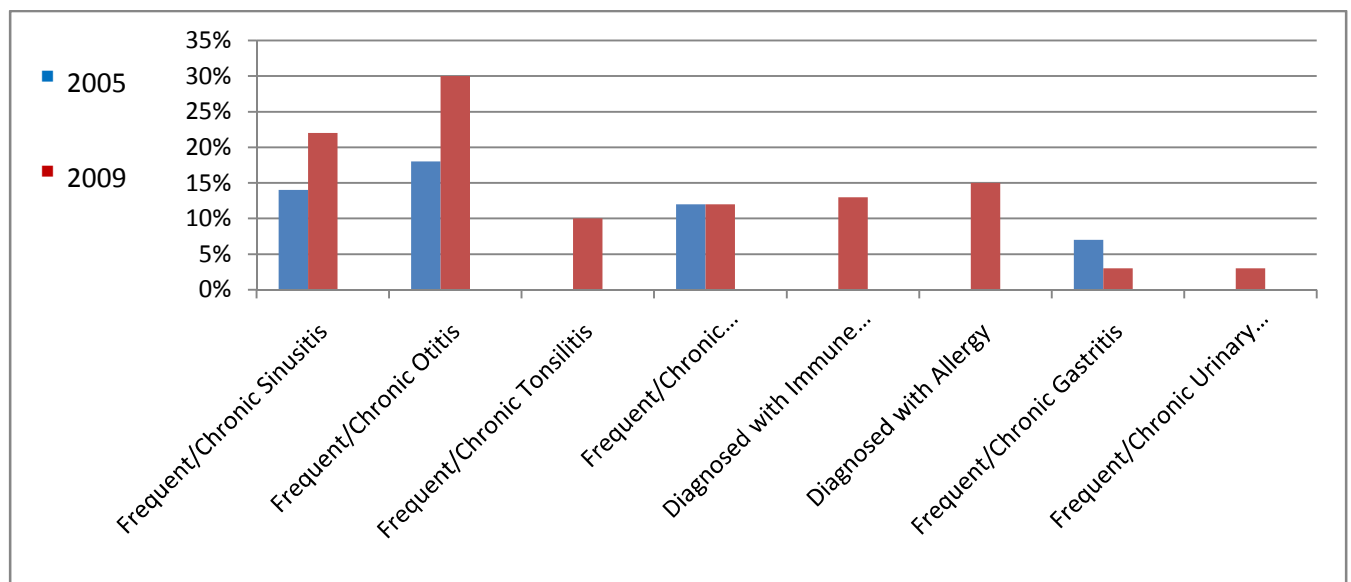
Joan V. Skluzacek, BA; Kathryn P. Watts, MSc; Susan E. Goodliffe, BA; Olivier Parsy; Karen Glenn; Angela P. Black, MD

Supporting Data for Poster

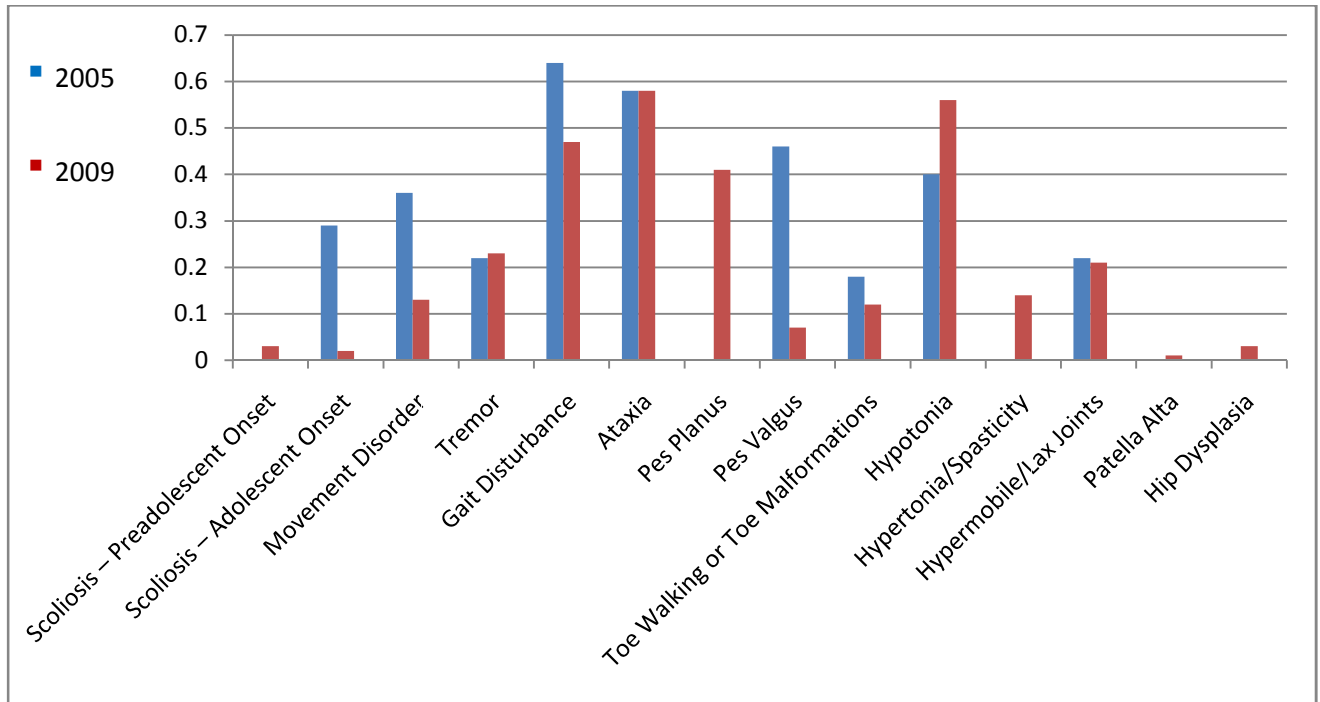
Concerns Regarding Development, Autistic Characteristics, and Communication



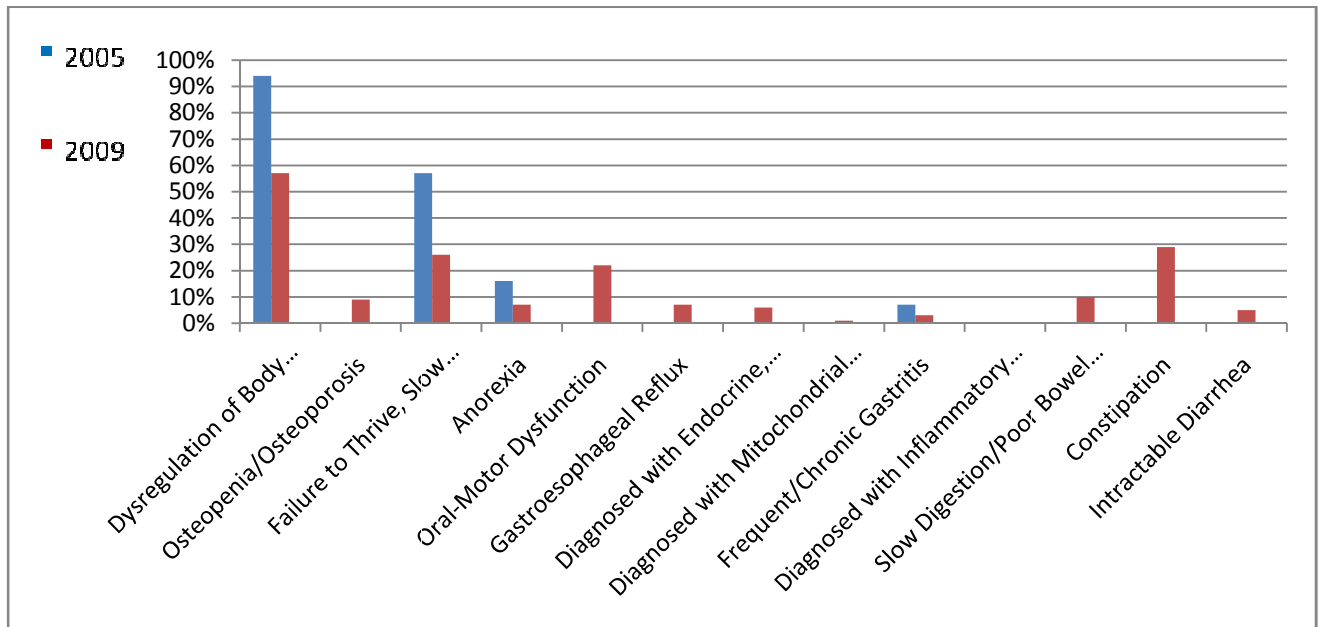
Concerns About Frequent/Chronic Infections and Immunity



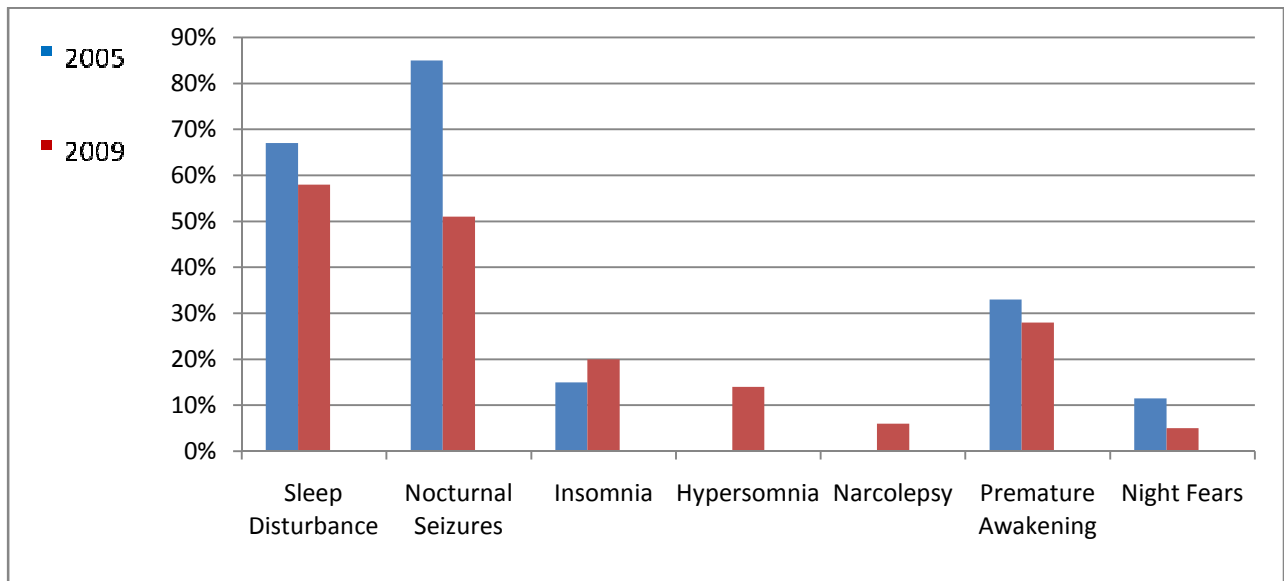
Orthopedic Concerns



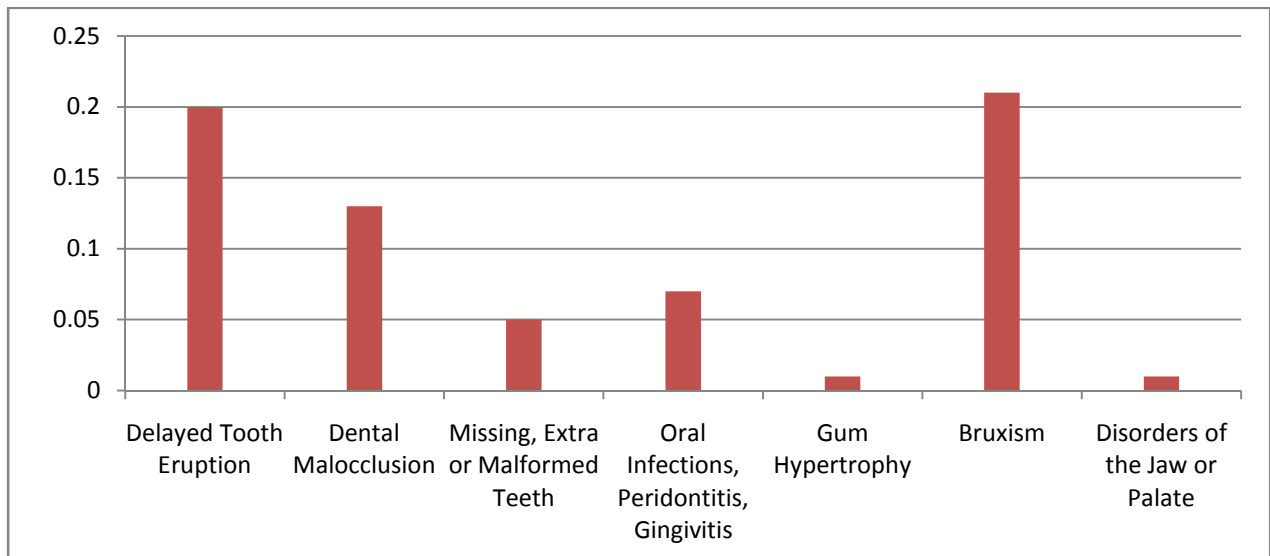
Concerns About Growth, Endocrine Function and Metabolism



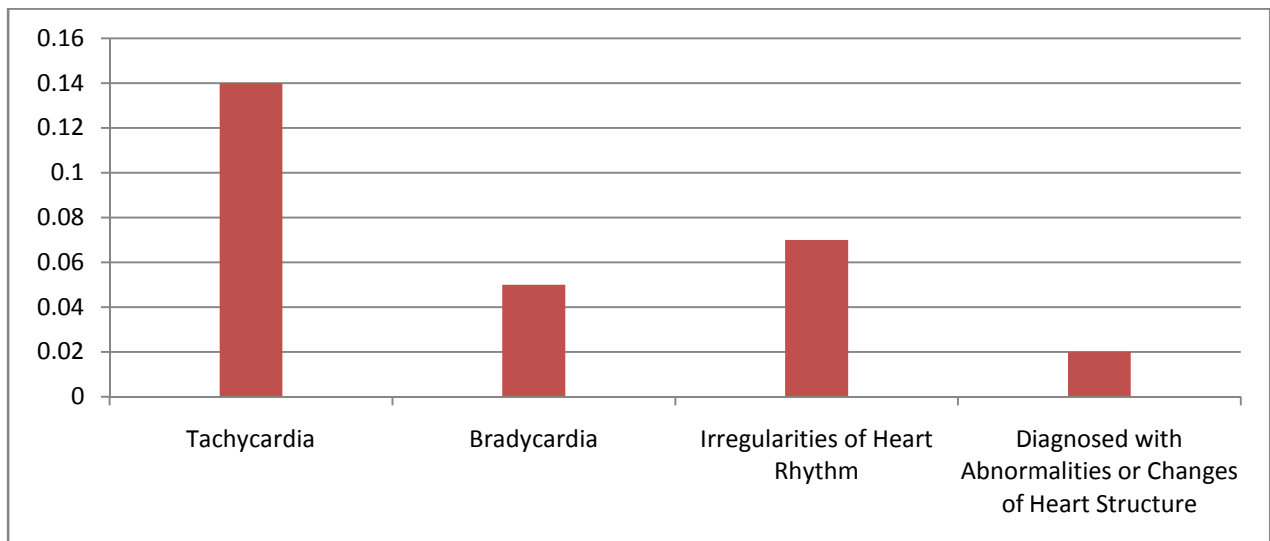
Sleep Problems



Dental Problems



Cardiac Concerns



Types of Medical Specialists That Have Been Involved in the Care of or Consulted Regarding the Care of IDEA League Children with Dravet Syndrome

Members of the IDEA League Family Forum who are parents of children with Dravet syndrome were invited to participate in a survey regarding the types of medical specialists that have participated in their child's care or that they have consulted regarding their child's care.

81 respondents participated between September 21 and October 1, 2009

	Medical Specialty	Percent of Survey Respondents Reporting Involvement of this Specialty
1	General Pediatrician – Primary Care Provider	100%
2	Developmental Pediatrician	2%
3	Neurologist/Epileptologist	100%
4	Endocrinologist/Metabolic Specialist	38%
5	Immunologist	22%
6	Infectious Disease Specialist	12%
7	Allergist	23%
8	Otolaryngologist (ENT)/Audiologist	43%
9	Ophthalmologist	4%
10	Developmental or Neuro- Ophthalmologist	28%
11	Developmental/Special Needs Dentist	27%
12	Sleep Specialist	20%
13	Developmental or Neuro- Psychiatrist/Psychologist	49%
14	Physiatrist/Specialist in Physical Medicine	7%
15	Physical Therapist	80%
16	Occupational Therapist	79%
17	Speech Pathologist	89%
18	Orthopaedist/Orthotist	41%
19	Podiatrist	2%
20	Dermatologist	3%
21	Cardiologist	35%
22	Pulmonologist	11%
23	Geneticist	63%
24	Emergency Medicine Specialist	32%
25	Intensivist (Critical Care Specialist)	38%
26	Gastroenterologist	32%
27	Urologist	14%
28	Dietician	54%
29	Specialist in Complementary Medicine (Osteopath, Chiropractor, Nutritionist, Massage Therapist, etc.)	46%

Symptoms and Conditions Found in Children with Dravet Syndrome In Addition to Epilepsy

Members of the IDEA League Family Forum who are parents of children with Dravet syndrome were invited to participate in a survey regarding the symptoms and conditions found in their child in addition to epilepsy. This was to update information gathered in 2005.

86 respondents participated between September 21 and October 1, 2009

	Symptom or Condition Reported	% Reporting in 2005 n = 65	% Reporting in 2009 n = 86	
1	Sleep Disturbance	67%	58%	
2	Nocturnal Seizures	85%	51%	
3	Insomnia	15%	20%	
4	Hypersomnia		14%	
5	Narcolepsy		6%	
6	Premature Awakening	33%	28%	
7	Night Fears	11.5%	5%	
8	Parent or Sibling with SCN1A Mutation		6%	
9	Child with DS has another genetic condition		5%	
10	Parent or sibling has another genetic condition		9%	
11	Development slowed down		70%	
12	Development regressed		35%	
13	Severe Developmental Delay	39%	40%	
14	Moderate Developmental Delay	29%	40%	
15	Mild Developmental Delay	30%	29%	
16	Diagnosed with Autism Spectrum Disorder	18%	21%	
17	Has Autistic Traits	40%	33%	
18	Socially Withdrawn	18%	10%	
19	Lack of Social Reserve/Overly Familiar to Strangers	47%	56%	
20	Perseveration	35%	52%	
21	Obsessions	24%	40%	
22	Self-stimulation	26%	20%	
23	Hyperactivity	20%	34%	
24	Does not play with toys appropriately	14%	30%	
25	Visual Sensitivity or Sensory Defensiveness	31%	19%	
26	Auditory Sensitivity or Sensory Defensiveness	14%	21%	
27	Tactile Sensitivity or Sensory Defensiveness	18%	23%	
28	Midline Shift Syndrome		3%	
29	Echolalia	18%	24%	
30	Aphasia	48%	28%	
31	Delayed Language/Communication Development	68%	83%	
32	Frequent/Chronic Sinusitis	14%	22%	
33	Frequent/Chronic Otitis	18%	30%	
34	Frequent/Chronic Tonsillitis		10%	
35	Frequent/Chronic Bronchitis and/or Pneumonia	12%	12%	
36	Diagnosed with Immune Abnormality	0	13%	
37	Diagnosed with Allergy		15%	
38	Hearing Loss		3%	
39	Severe Photosensitivity	23%	10%	30%
40	Mild to Moderate Photosensitivity		20%	
41	Pattern Sensitivity	12%	12%	
42	Frequent/Chronic Inflammation of Eye Tissues		6%	
43	Optic Neuropathy		1%	
44	Retinitis Pigmentosa		0	

