

Medical Clinic for children with autism: update 2013-2018

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Vancouver, November 2018*

No conflict of interest

- ◆ no financial involvement in clinics
- ◆ no corporate sponsorship

Learning objectives

- ◆ think of autism when patient seems odd or difficult in their way of interacting with you
- ◆ learn some strategies that can make health care less stressful for you and your autistic patients
- ◆ encourage collaboration with caregivers, educators, and other health care professionals when trying to meet the health care needs of patients with autism

autism = atypical

- ◆ if your patient seems odd or difficult to talk with, think about the possibility of autism, which is not always diagnosed early
- ◆ Autism= **significant deficits in THREE domains:**
- ◆ 1. social interaction [getting along with other people]
- ◆ 2. communication [talking]
- ◆ 3. significant restriction in play interests & activities
- ◆ Autism is a behavioural diagnosis; biologically they are all different and need individual approaches, not 'one size fits all'

Other causes of atypical behaviour

- ◆ All of these contribute to atypical behaviour, +/-autism:
- ◆ poor eye contact: vision impairment
- ◆ ignores your requests: hearing impairment
- ◆ seems spaced out: partial or absence seizures
- ◆ severe hyperactivity: autistic features can be hard to spot if the patient is destroying the office or endangering themselves by running into traffic

Clinic visits 2013-2018

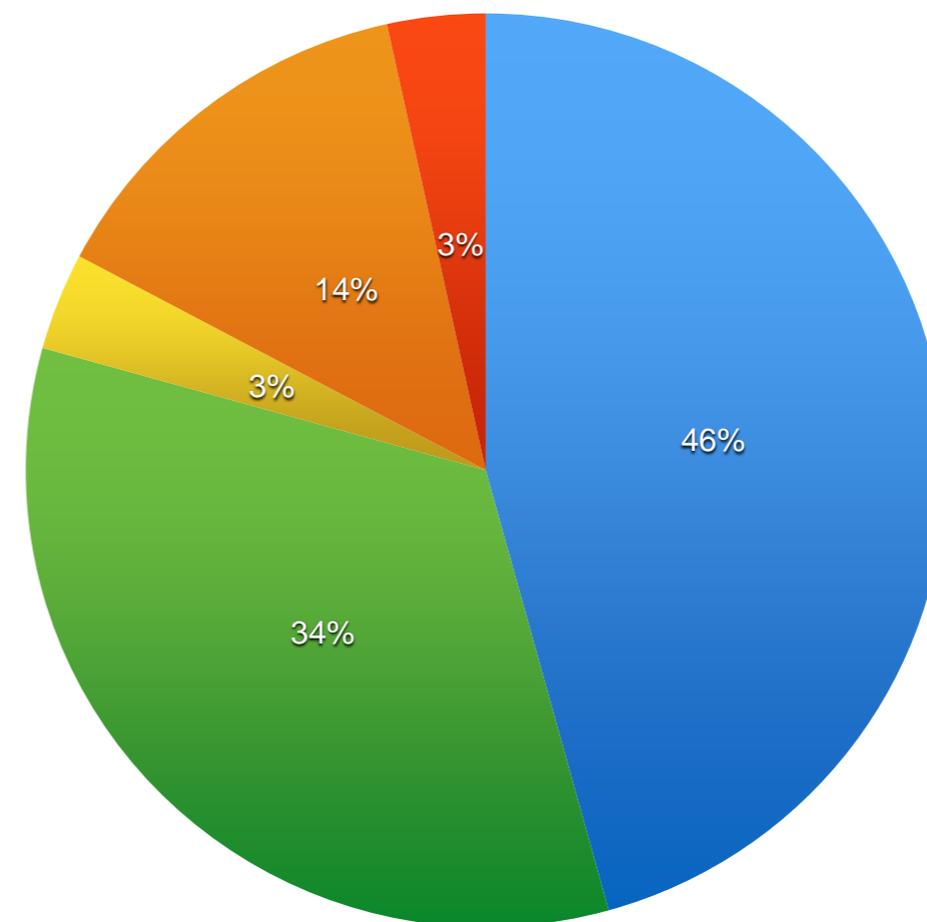
- ◆ 120 different children for total of 247 visits
- ◆ 91 new patients, 29 seen previously
- ◆ each child and family see by pediatrician and nutritionist working together

Where do our patients come from?

MCH referral sources

ER	4
PCC/RCC	9
neurology	2
psychiatry	23
developmental pediatrics	7
other specialties	8
MCH total	53

Sources of referral to medical autism clinic 2013-2018



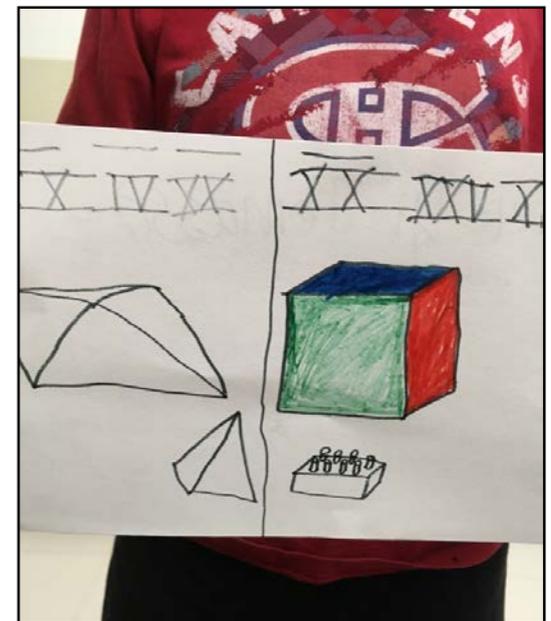
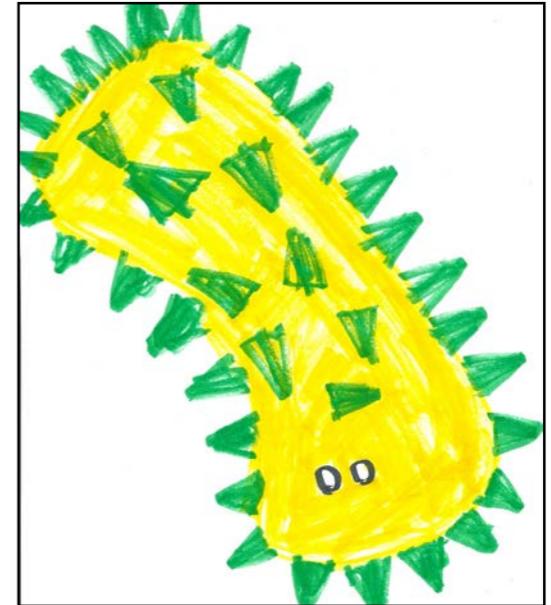
- MCH total
- community peds assoc. with MCH
- other institutions
- other physicians
- other [OT, ATEDM, parents]

Prepare for the visit: Autism Canada Physician Handbook

- ◆ minimize waiting time to avoid patient melt-down
- ◆ quiet room without windows, bright lights or music
- ◆ be alert for your own safety: upset autistic patient may Head-butt, Bite, Kick, Spit, Punch, Pull hair, Bolt
- ◆ I would add: room with NO carpet [I've never needed to call security, but have needed housekeeping.....], room without annoying buzzing noises, wear sensible shoes that let you move fast, long sleeves & long pants to avoid scratches

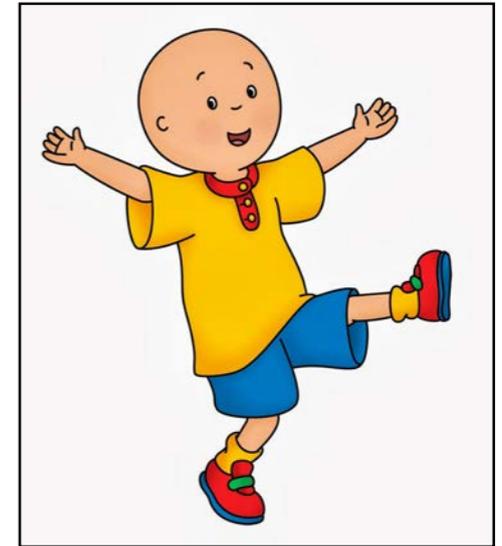
prepare for the visit: the accompanied patient

- ◆ ask the caregiver to bring:
- ◆ an extra person to look after the patient while the caregiver explains their medical concerns to you
- ◆ entertainment for the patient [favourite games or videos on phone or tablet]
- ◆ I always provide paper and washable markers because I like to see the particular interests of my patients [hand dryers, clocks, bacteria, sinking of Titanic...]
- ◆ clear the room of breakable/ expensive/ damageable objects [hide your computer]



Appropriate entertainment

- ◆ developmental disabilities don't exclude adolescent interests
- ◆ Shanujah & People magazine vs Marvin Cedric & Caillou
- ◆ Mila & the Prince from Frozen: 'the boy will check my ears'
- ◆ Jun Tao and queries about STDs



the unaccompanied patient

- ◆ introduce yourself to the patient and explain why you are meeting with them; ask if they can tell you why they have come to see you
- ◆ try to establish what language patient understands by watching their facial expressions as you try French, English, Italian, signing;
- ◆ if no reaction try printing or using screen of phone, tablet, or computer;
- ◆ watch their eyes to see if nystagmus or abnormal eye movements suggesting vision impairment



Rule 1. Avoid surprises

a, For autistic youth: Repeat, rehearse, be visual

i. have their parent/ educator/ normal sibling demonstrate each part of the physical exam, step by step, before you examine them

ii. have the parent or educator take photos of the doctor and the examining room to show the patient before each visit

iii. have the parent or educator practice the exam routine at home or at school before each visit

b. For blind youth:

i. introduce yourself

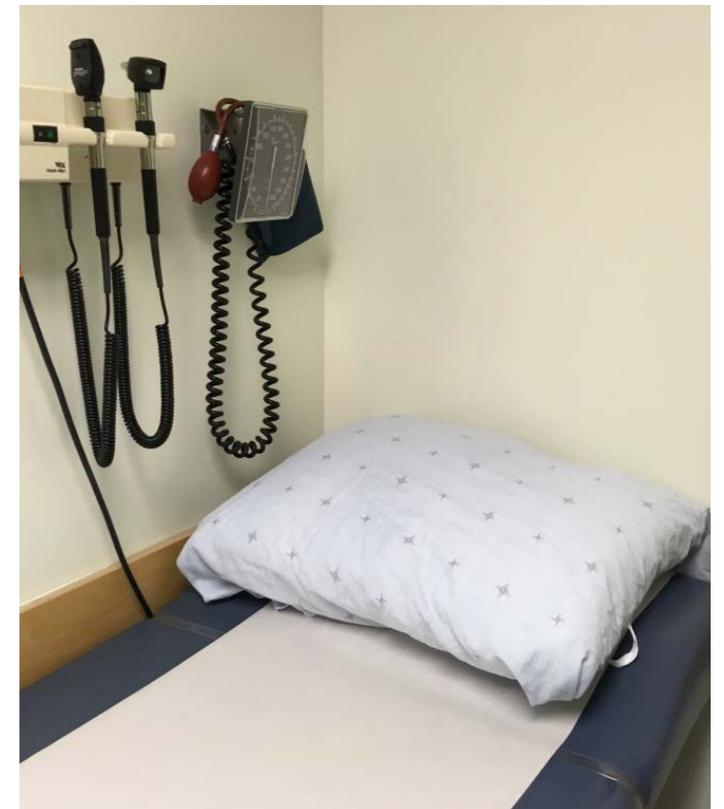
ii. say what you are going to do before you touch them

iii. put the kid's hand on your stethoscope, otoscope etc. to let them feel it before you touch them with it



Rule 2. Minimize sensory aversions

- a. listen to the chest and palpate the abdomen initially over a thin T- shirt then when this is accepted, progress to listening to and palpating bare skin**
- b. put a pillow under the patient's head when the youth has to lie down for an abdomen exam [no pillow? use a rolled up coat, backpack, or mother's purse] - abdomen muscles will relax and allow a meaningful exam**
- c. for ear exam, place the doctor's thumb on the ear, adjacent to the ear canal, and rest the otoscope speculum on the thumb, do not jam the otoscope speculum into the patient's ear canal, just direct the angle of light onto the ear drum**



Rule 3. Reward compliant behaviour

a. verbally: reinforce with ‘good job’, ‘well done’, ‘bravo’

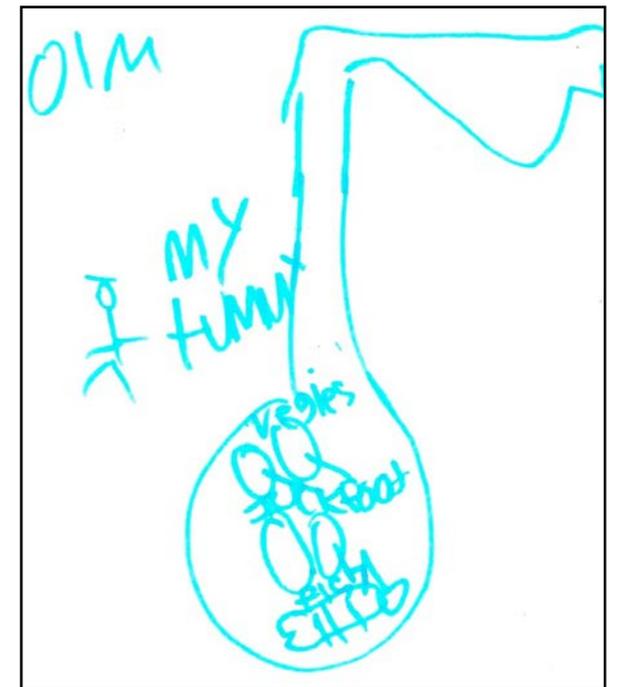
b. give a treat tailored to that patient’s preferences, e.g. Ashton [visually impaired & autistic]: when I ask him to open his mouth, Ashton says ‘open mouth say Ah’ , Ashton does it, then says, ‘want Oreo cookie now’, and is given his Oreo cookie by his teacher

Matthew [medical autism clinic] hates to lie on the table and is aversive to abdominal exam; I know he is fascinated by hand dryers so I collect photos of them from all over North America. Matthew agrees to lie down and have me palpate his abdomen in return for my assistant showing him the photos of hand dryers [‘That’s Halifax public gardens’ Matthew says]



Look for non-verbal cues

- ◆ watch facial expression as you palpate the abdomen or move limbs; patients with autism may not complain but you can see a grimace or wince with discomfort
- ◆ children with autism may not complain of pain
#1: a parent noted her son did not use his arm for a week; x-ray showed a fractured humerus
- ◆ children with autism may not complain of pain
#2: a boy was brought to the ER because he had stopped walking; examination found peritonitis due to a ruptured appendix



Autistic patients may reuse gestures

- ◆ original gesture generalizes to mean anything unpleasant
- ◆ Bradley & Sandifer syndrome: extensor spasms with GERD, then with incarcerated hernia, pancreatitis, cervical adenitis, finally at age 5 when disliked questions from social worker
- ◆ Thomas and hitting self in face: at age 3 from eye pain of glaucoma; recurred age 7 years: eye pressure normal, looked worried not laughing, then spaced out briefly = partial seizures with unpleasant prodrome/ aura

time and patience needed

- ◆ may not be able to see everything on a first visit, but show the patient your expectations, and over time most can be examined
- ◆ cooperation between caregivers and medical staff is needed to understand the causes of behavioural deterioration and remedy underlying medical problems.
- ◆ sometimes need to organize ear exam or blood tests during anesthesia for dental work

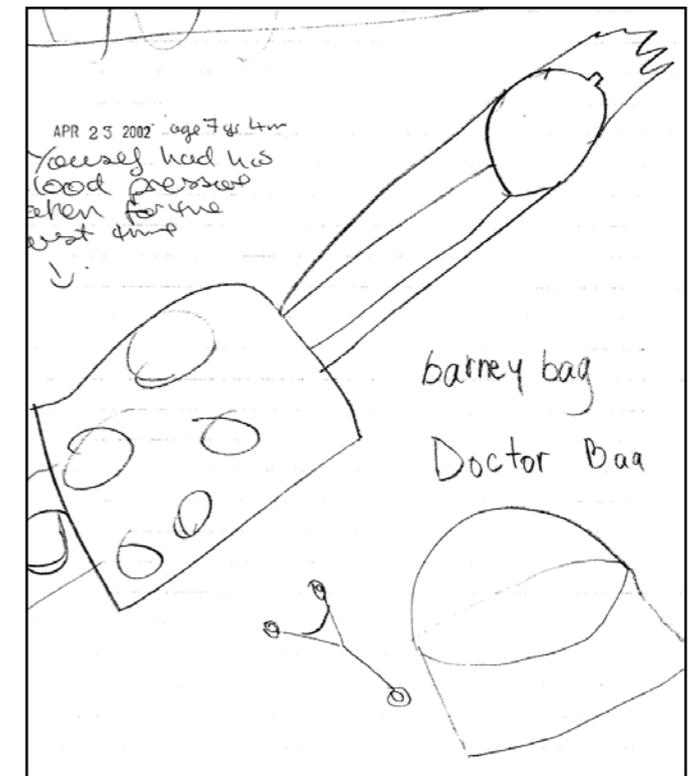


What families request...

1. Family panel Early Years conference UBC, January 2018: family members of children with developmental disabilities [autism with Prader Willi, autism with VACTERL, an adopted child with autism] explained what they liked and what they disliked about interactions with medical staff.
2. They disliked being told very negative outcome predictions at birth. [e.g. Your child will never walk]. They disliked doctors saying negative things in front of their child, who may be able to hear even if unable to talk.
3. They wanted doctors to introduce themselves to the parent and the child. They wanted appointment times to be arranged to suit their child's needs. They did not want open shelves or accessible medical equipment in the exam room, which their child would want to touch. They wanted health professionals to recognize subtle symptoms of anxiety in their children: blinking, stuttering, outburst behaviour.

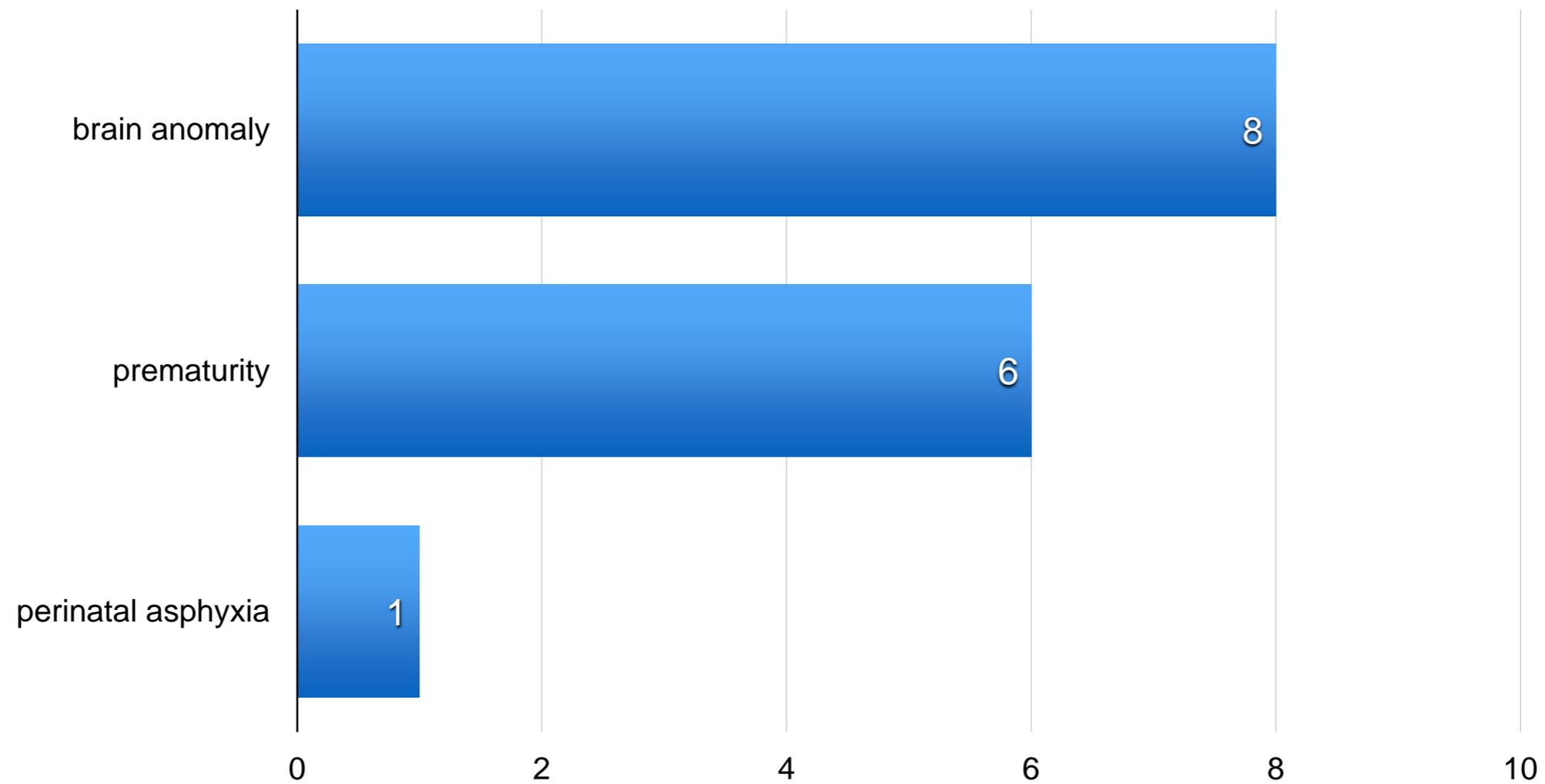
autism & medical co-morbidity

- ◆ seizures: 30%, at some point in time
- ◆ deaf, blind, CP, motor impairments
- ◆ constipation, GE reflux: more common in autism than their normal siblings
- ◆ picky eating, malnutrition
- ◆ obsessive eating and obesity
- ◆ teenage girls with menses: behaviour, hygiene issues, seizures



Neurological risk factors: 12.6%

Neurological risk factors 15 out of 119 children

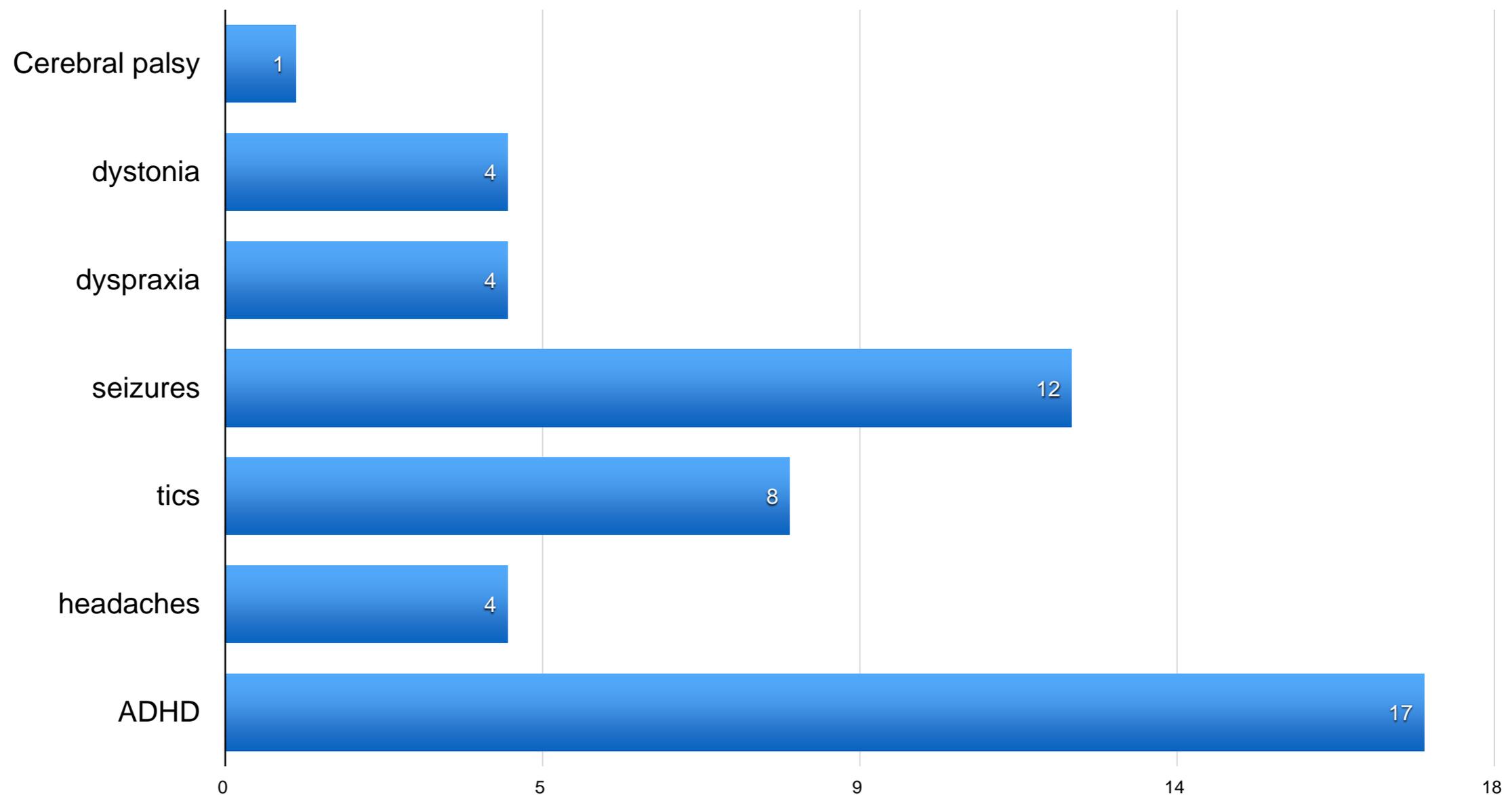


Neurological risk factors

- ◆ Brain anomalies our patients: diverse, including agenesis of the cerebellar vermis [2], microcephaly [2], cerebral dysgenesis, prenatal CVA causing extensive loss of R. parietal parenchyma, neurodegeneration with brain iron accumulation, and Chiari malformation
- ◆ Prematurity: recent review of 18 studies was published in Pediatrics in August 2018, showing that 7% of children born before 32 weeks gestation had a diagnosis of ASD by age 5 years
- ◆ Perinatal asphyxia: Australian study found 8% of children with a history of perinatal asphyxia had a diagnosis of ASD by age 5 years

Neurological co-morbidity: 42%

Neurological comorbidity 50 out of 119 children



gastrointestinal co-morbidity

constipation	37
diarrhea NYD	24
Crohns	2
Celiac disease	1?
gassy	10
vomiting	1
GERD	3
rumination	1
pica	5
stool parasites	2
gallstones	1

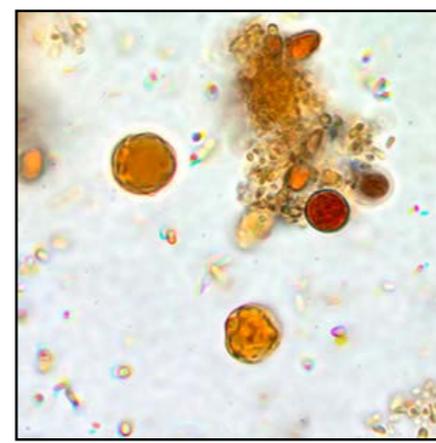
GI problems affected 82
out of 120 children: 68%

Pica: symptom & cause of medical problems

- ◆ eating sand, earth, paint chips
- ◆ can be a sign of sensory cravings or a symptom of iron deficiency
- ◆ child can ingest tiny eggs of parasites with earth or sand
- ◆ 2 of our patients had parasites in stool samples



raccoon roundworm



blastocystis



ascaris roundworm egg

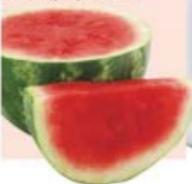
help for gas & diarrhoea

- ◆ some children and adults have difficulty digesting complex sugars and carbohydrates 'FODMAP's
- ◆ less gas, diarrhoea, and cramps can make children less irritable and calmer in behaviour

Foods suitable on a low-fodmap diet

fruit	vegetables	grain foods	milk products	other
fruit banana, blueberry, boysenberry, canteloupe, cranberry, durian, grape, grapefruit, honeydew melon, kiwifruit, lemon, lime, mandarin, orange, passionfruit, pawpaw, raspberry, rhubarb, rockmelon, star anise, strawberry, tangelo <small>Note: if fruit is dried, eat in small quantities</small> 	vegetables alfalfa, bamboo shoots, bean shoots, bok choy, carrot, celery, choko, choy sum, eggplant, endive, ginger, green beans, lettuce, olives, parsnip, potato, pumpkin, red capsicum (bell pepper), silver beet, spinach, squash, swede, sweet potato, taro, tomato, turnip, yam, zucchini herbs basil, chili, coriander, ginger, lemongrass, marjoram, mint, oregano, parsley, rosemary, thyme	cereals gluten-free bread or cereal products bread 100% spelt bread rice oats polenta other arrowroot, millet, psyllium, quinoa, sorghum, tapioca 	milk lactose-free milk*, oat milk*, rice milk*, soy milk* <small>*check for additives</small> cheeses hard cheeses, and brie and camembert yoghurt lactose-free varieties ice-cream substitutes gelati, sorbet butter substitutes olive oil	tofu sweeteners sugar* (sucrose), glucose, artificial sweeteners not ending in '-ol' honey substitutes golden syrup*, maple syrup*, molasses, treacle <small>*small quantities</small> 

Eliminate foods containing fodmaps

excess fructose	lactose	fructans	galactans	polyols
fruit apple, mango, nashi, pear, tinned fruit in natural juice, watermelon sweeteners fructose, high fructose corn syrup large total fructose dose concentrated fruit sources, large serves of fruit, dried fruit, fruit juice honey corn syrup, fruisana 	milk milk from cows, goats or sheep, custard, ice cream, yoghurt cheeses soft unripened cheeses eg, cottage, cream, mascarpone, ricotta 	vegetables artichoke, asparagus, beetroot, broccoli, brussels sprouts, cabbage, fennel, garlic, leek, okra, onion (all), shallots, spring onion cereals wheat and rye, in large amounts eg, bread, crackers, cookies, couscous, pasta fruit custard apple, persimmon, watermelon miscellaneous chicory, dandelion, inulin, pistachio	legumes baked beans, chickpeas, kidney beans, lentils, soy beans 	fruit apple, apricot, avocado, blackberry, cherry, longon, lychee, nashi, nectarine, peach, pear, plum, prune, watermelon vegetables cauliflower, green capsicum (bell pepper), mushroom, sweet corn sweeteners sorbitol (420), mannitol (421), isomalt (953), maltitol (965), xylitol (967) 

help for constipation

- ◆ hydration: need to drink enough to soften bowel movements
- ◆ dietary fibre: not always easy for picky eaters
- ◆ Laxaday: PEG 3350 pulls water into bowel movements, making them softer



Nutritional problems: 85%

restrictive diet	38
picky eaters	43
food intol./allergy	5
FTT	12
obesity	13
nutrit. defic. measured	5
IDDM	1
dysphagia/ poor chew	6

Nutritional issues affected
103 out of 120 children

Restrictive diets

- ◆ Parents may choose a restrictive diet because of their child's GI symptoms, because they read it on internet, or because they themselves are vegan
- ◆ No milk: lack vitamin D +/- calcium
- ◆ No wheat: lack folic acid
- ◆ No meat/ chicken/ fish: lack B12, iron

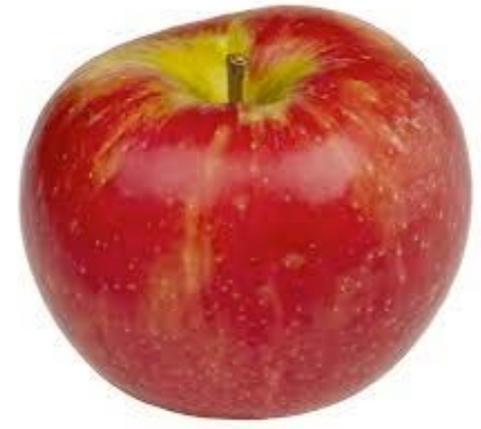
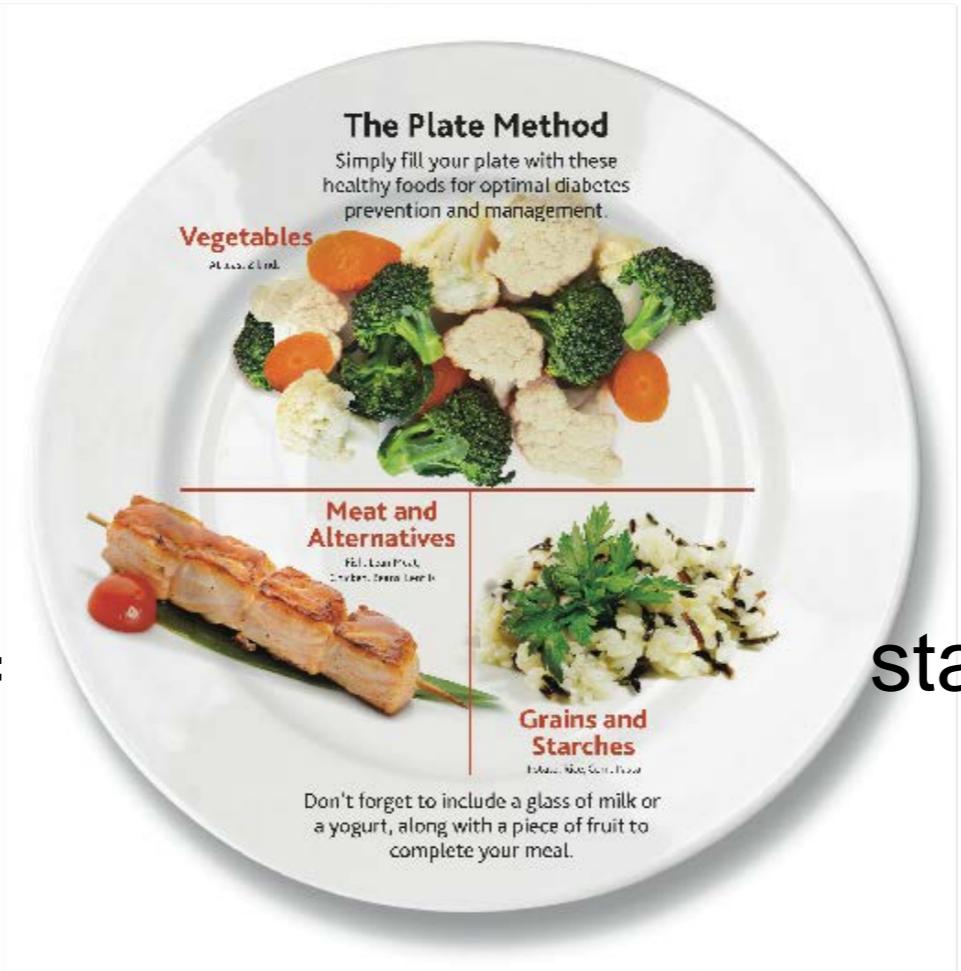
advice for obesity: the dietician plate



What's on *your plate*?



meat portion=
size of the
eater's palm



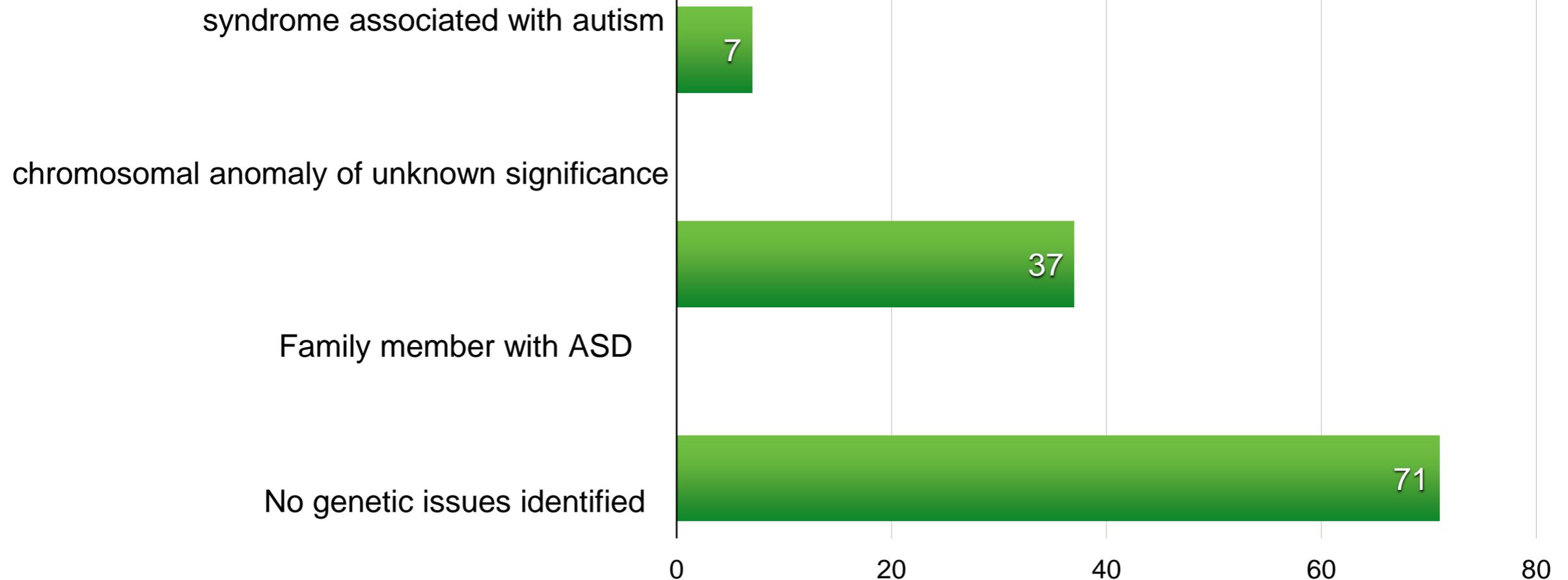
starch portion =
size of the
eater's fist

Cases to discuss

- Antonio: environmental sensitivities & leg pain
- Ahmed: celiac or gluten intolerant
- Leonor eats dirt and gets a parasite
- Lucas and the low FODMAPS diet
- Annabelle: acid reflux and more....
- Caleb: the very picky eater
- Ben: morbid obesity

genetic factors: 40%

4 genetic issues 120 children

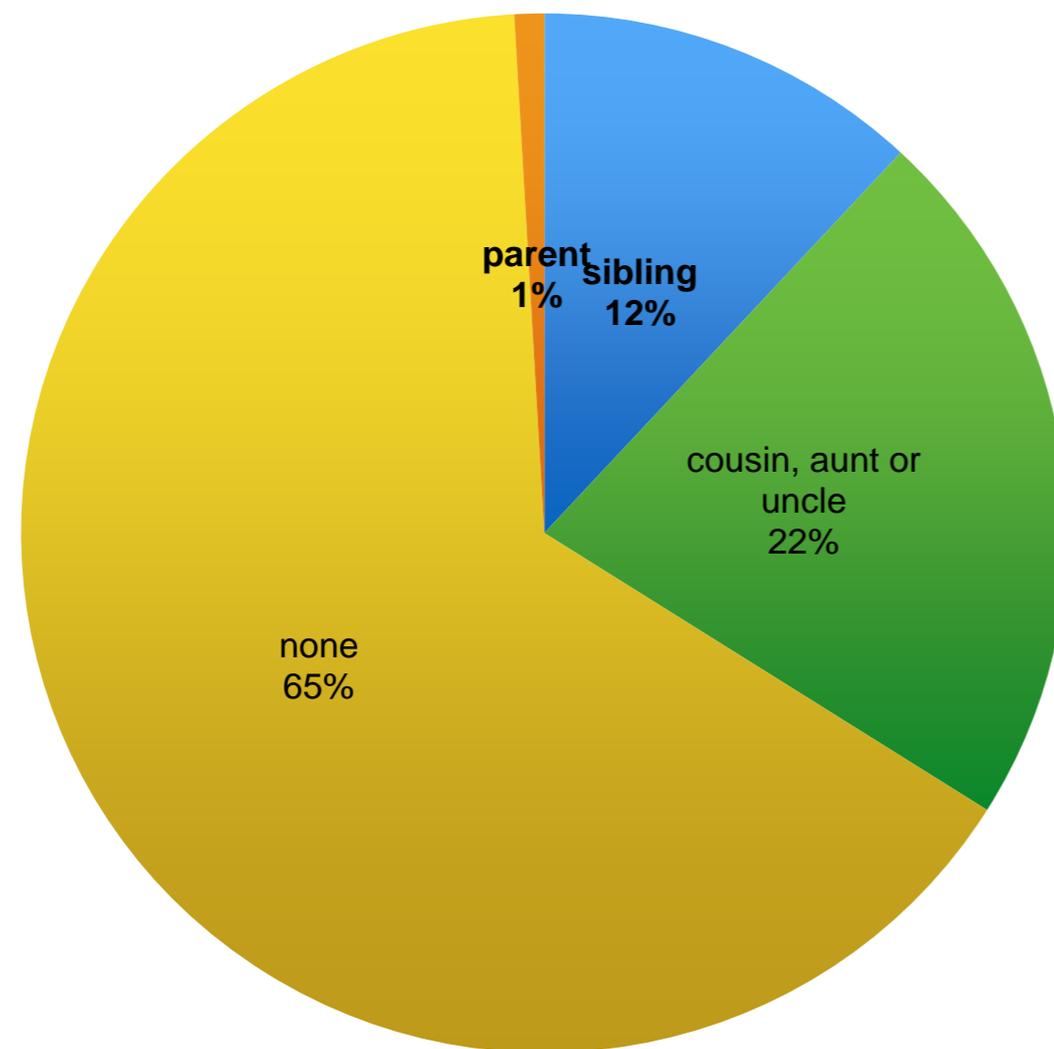


genetic syndromes with ASD

- ◆ **Bardet- Beidl:** ciliopathy associated with cone-rod dystrophy, progressive vision impairment [retinitis pigmentosa], polydactyly, kidney abnormalities, obesity, cognitive impairment
- ◆ **Joubert syndrome** [brother and sister]: ataxia, hyperventilation, low muscle tone, eye problems including oculomotor apraxia and retinal dystrophy, kidney malformations, cognitive impairment, seizures
- ◆ **CHD8 mutations** [> 30 different mutations of chromatin helicase DNA binding protein known, found in 15/6,000 children with autism] on chromosome 14q11: large head size, cognitive impairment, gastrointestinal problems particularly constipation [enteric neurons affected?]

Family members with ASD: 31%

Family members with ASD



- sibling
- cousin, aunt or uncle

38 of our autistic patients had family members with autism: 31%

Networking: teaching medical trainees

- ◆ part of my goal is to train young doctors to provide medical care to patients with autism
- ◆ most are McGill university trainees but a few come from other universities

medical autism clinic attendees 2013-2018

mcgill med 3 students	39
developmental pediatrics med 4 students	12
community pediatrics residents	12
developmental pediatric residents	49
family medicine residents	1
psychiatry residents	11
neurology residents	4
genetics residents	2
total	130

handout for trainees

How to examine youth with special needs

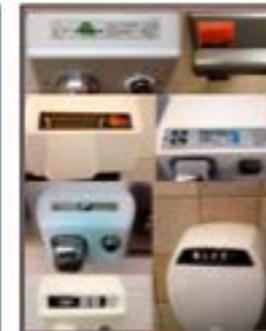
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2. Minimize sensory aversions

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- b. give a treat tailored to that patient's preferences, e.g.
Ashton [Philip Layton Dr Class]: when I ask him to open his mouth, Ashton says 'open mouth say Ah', Ashton does it, then says, 'want Oreo cookie now', and is given his Oreo cookie by his teacher
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Networking with community resources: U. of M. pharmacology student project

Comment optimiser les soins d'un patient présentant un trouble du spectre de l'autisme (TSA)?

La relation entre les professionnels de la santé et les patients présentant un TSA pourrait être plus optimale. D'un côté, ces patients sembleraient rencontrer certains obstacles dans la prestation de leurs soins (1). De l'autre, les professionnels de la santé ne trouveraient pas toujours adéquate leur formation sur le sujet et ressentiraient un inconfort lorsqu'ils doivent traiter cette clientèle (2).

Certaines stratégies somme toute simples pourraient faire en sorte que le patient et le professionnel ressortent plus satisfaits de leur relation de soins. En premier lieu seront présentées des stratégies générales élaborées pour la médecine, mais qui s'appliquent à toutes les professions. Puis, seront présentées des stratégies plus spécifiques à une profession (médecine dentaire, optométrie, pharmacie).

- ◆ University of Montreal pharmacology students organized a talk and a website in March 2018 to provide information to health care students in various disciplines about working with patients with autism

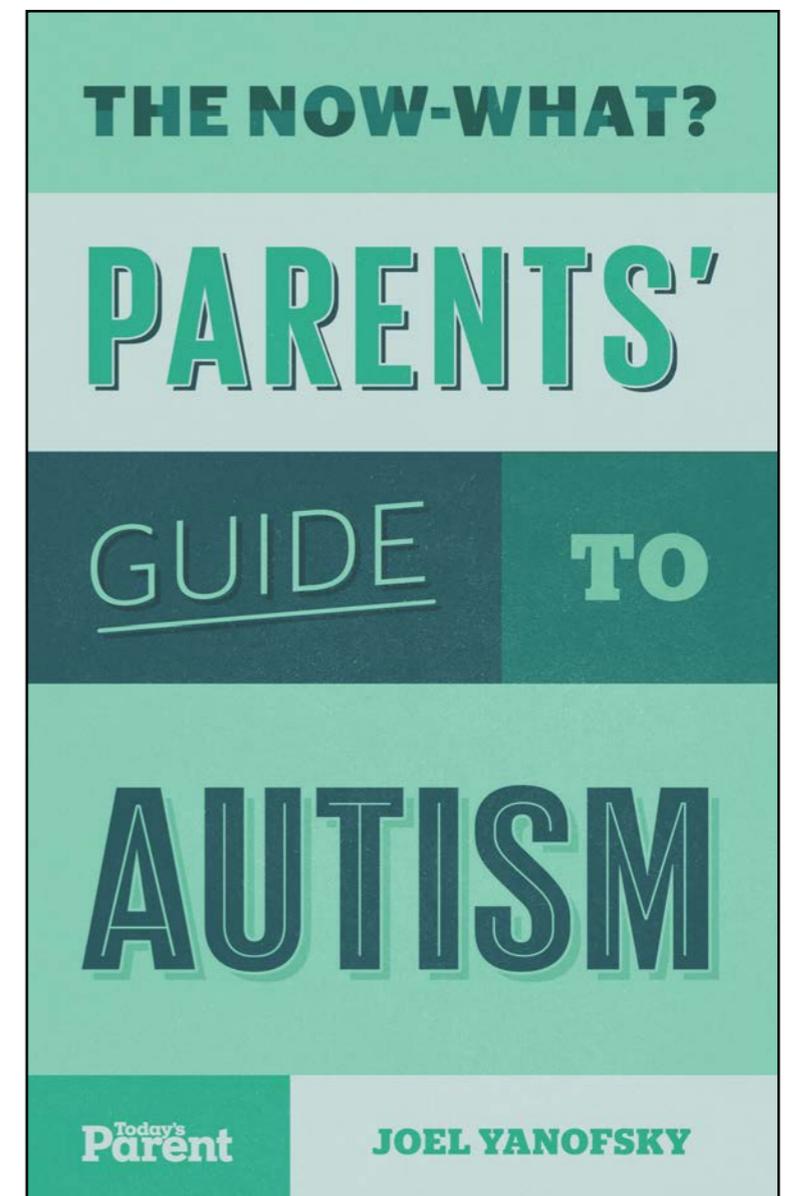
Networking with community resources: Montreal Tamil Health Initiative



- ◆ Montreal Tamil Health Network organized an afternoon of seminars by medicine and rehab staff for parents in April 2018

Networking with community resources: Montreal author & parent

- ◆ Montreal author Joel Yanofsky interviewed parents, paediatricians, nutritionists, and autism researchers from coast to coast in Canada to give parents a practical guide when their child receives a diagnosis of autism
- ◆ published as an e-book by Amazon, I-Books, and Kobo in April 2018



in conclusion:

- ◆ think of autism when patients are odd or difficult
- ◆ prepare the examining room for safety *and* entertainment
- ◆ avoid surprises
- ◆ use strategies to minimize sensory aversions
- ◆ reward compliant behaviour
- ◆ look for medical co-morbidity
- ◆ look for non-verbal cues of pain or distress

References

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- ◆ website from U. of Montreal to help health professionals interact with autistic patients: <https://pha1416.wixsite.com/optimiser-soins-tsa>