vol. 8 no. 2 | summer 2022

CPNP NASPGHAN
Council for Pediatric Nutrition Professionals

Executive Committee Message:

I hope this newsletter finds you well and enjoying summer! We are very excited that it looks like we will be having an in-person meeting this fall. It will be wonderful to see many of you in person again and we will be celebrating the 50th anniversary of NASPGHAN!! This Annual Meeting in Orlando is sure to be a very special event.

One of our main goals for 2022 was to begin our mentor program by pairing experienced members with either new members or members who were new to their area of practice. I am pleased to say that we were able to match our first mentor/mentee and were able to have them meet virtually. Our mentor/mentee pair are off to a great start and we look forward to expanding the program in the future. If you are interested in being a mentor or mentee, please reach out to us via email (cpnp.naspghan@gmail.com).

We are also very happy to work with our NASPGHAN colleagues on several other projects including an up-coming joint webinar, ongoing Nutrition Pearls and a combined CPNP-NASPGHAN Formula Task Force to address the current shortages. CPNP is honored to have Phuong Huynh MS, RD, CSP and Meghan Murphy, RD serving on the Formula Task Force subcommittee. CPNP members contributed to the formula substitution list that NASPGHAN approved and disseminated on the day the formula recall occurred and has since been extensively updated. This list/table was eventually used at the White House! A very sincere thank you to CPNP's own Bailey Koch for her willingness to contribute information at short notice that kick-started this contribution and for sharing her expertise with our NASPGHAN colleagues.

Nutrition Pearls are another important contribution by CPNP. We get positive feedback from our NASPGHAN and APGNN colleagues after every Pearl is released. We have even noted our membership increases. We consider them a vital part of CPNP to educate and support our colleagues in a meaningful way. If you are considering a topic or looking for a way to become more involved with CPNP, we would love to have you complete a Pearl.

Finally, a very warm welcome back and a huge thank you to Dr. Justine Turner for volunteering to be the CPNP liaison to NASPGHAN. Dr. Turner served as our liaison in the past and we could not be happier to have her back! She is a true advocate for nutrition and RD's.

Best wishes for a safe and healthy summer!

Sincerely,

Carmyn Thompson

Carmyn Thompson, RD, LDN, CSP
CPNP President

secretary treasurer's report

Megan Murphy, RD

CPNP continues to grow with over 200 active members. We are looking forward to seeing everyone at the Annual Meeting this year, celebrating NASPGHAN's 50th anniversary!

Please continue to spread the word about CPNP membership, and remember it includes discounts for the NASPGHAN Annual Meeting and CPNP Nutrition Symposium, access to our listserv, newsletters, monthly Nutrition Pearls, research grant opportunities and Nutrition University (N^2U) attendance.

New members can download an application here. Our annual membership fee is $40, with an option for a yearly subscription to *JPGN* for $65. For our current members, please remember to update and complete your profile so that your area of practice/specialty is up to date so we can reach out to you for speaking opportunities and other CPNP projects!

We are always looking for volunteers for Hot Topics in the newsletters, Nutrition Pearls, and of course, the Annual Meeting (planning, presenting, moderating, posters - you name it). So if you've been looking to get more involved with CPNP, please reach out to us at (cpnp.nasphgan@gmail.com). Volunteering is a great way to become more involved, network with other CPNP members, promote the importance of RDs work and also looks great on your CV!

in this issue

president-elect REPORT

ABIGAIL LUNDIN, MS, RD

CPNP is now accepting nominations for its CPNP Dietitian of Excellence Award!

Nominees will be evaluated on design and implementation of a new method, process, approach, or application that solves a problem in nutrition; research; teaching; public dissemination of education; publication, and overall impact of nominee's activities. Nominees may also be considered for providing professionally relevant cultural, educational, humanitarian, patriotic, environmental, ethical, or conservation contributions to their community.

Only CPNP Registered Dietitians in good standing are eligible for this award. This award will be given at the 2022 CPNP Nutrition Symposium in Orlando, FL in October. Nominees should not be members of the conference planning, executive, or awards committees at the time of recognition.

The nomination letter should be limited to 250 words. The nominee may solicit a letter or a nomination may be completed without applicants' knowledge. The letter should speak to the selection criteria, including a clear statement about the nominee's achievements in relation to at least one of the criteria above and why he or she is being recommended. Email nominations to (cpnp.naspghan@gmail.com) by July 31, 2022.

media REPORT

NICOLE MARTIN, RD, CSP, CD

The CPNP Member Center webpage has been updated! Check it out for more information on research, clinical resources, how to get involved with CPNP, and much more!

Find CPNP on social media! Use the handles below and follow us for general updates and the latest CPNP info. Contact Nicole at (nmartin@chw.org) if you have information that you would like to share on our social media sites.

- **Facebook: cpnp.naspghan**
- **Instagram: cpnp_naspghan**
- **Twitter: cpnp_naspghan**

CPNP members can join our private CPNP Members Facebook group page. Find our private CPNP Members group here.

Join the CPNP Listserv to learn more about upcoming events, participate in discussions about clinical findings and difficult cases, and more! Email (cpnp.naspghan@gmail.com) to join the Listserv.

program chair REPORT

KIRSTEN JONES, RD, CSP, LD

We are thrilled to announce that this year's symposium schedule for Orlando, FL is now posted on the Annual Meeting website!

Registration for the CPNP Nutrition Symposium includes a full day of CPNP events on Saturday October 15, as well as access to the NASPGHAN Annual Meeting events on October 14 and 15.

This year is particularly special because we are celebrating the 50th anniversary of NASPGHAN, the 10th anniversary of the CPNP Nutrition Symposium, and our first in-person conference in 2 years.

Several talks from this year's meeting will be recorded for online viewing later. Some highlights are:

- Advice for navigating formula shortages and other crises
- Growth chart interpretations
- Nutrition support for challenging patients
- Utility of uncommon anthropometric measurements
- International Dysphagia Diet Standardization Initiative (IDDSI): a hands-on workshop to play with food!
- Diet & IBD: getting into the details of the many therapeutic diets
- A special collaboration with NASPGHAN with topics including EoE, IBS, blenderized tube feeds, and fad diets.
- Our first CPNP Awards Presentation
- CPNP Abstracts & Posters

Check out this link for the full CPNP Symposium schedule and this link for the full NASPGHAN Annual Meeting schedule.

Register here! See you in Florida!

communications REPORT

SHARON WESTON, MS, RD, CSP, LDN

Continue to keep an eye out for two newsletters per year —Summer and Winter. Thanks to those who authored the Hot Topics and N²U summary for this newsletter: Vanessa Weisbrod, Dr. Nan Du, Lauren Jalali and Nicole Misner.

We want to hear from you! Please let us know if you have published research. In addition, reach out if you have ideas for future newsletter topics or important bulletins you would like to share with CPNP members. We are looking for volunteers to help with editing future newsletters. Please contact Sharon Weston if you are interested (Sharon.weston@childrens.harvard.edu).

clinical practice REPORT

BAILEY KOCH, RD, CSP, LD

The Pearls committee is in need of volunteers for new Pearls as well as topics of interest. Creating a Pearl is a quick and easy process. Please reach out to Bailey Koch (bailey@atlantapediatricnutrition.com) if interested in creating a Pearl or if you have any ideas for new topics.

research chair REPORT

JEN SMITH, MS, RD, CSP, LD, LMT

CPNP will be reviewing and choosing abstracts to feature at the upcoming NASPGHAN meeting. This year will be the first year we will feature an abstract of distinction. The Research Committee and a few additional members of CPNP will participate in the NASPGHAN Foundation Grant Review in August where recommendations for grant awards will be given to the NASPGHAN Foundation. We are excited to see what projects RDs submit and who will be the recipient(s) at the NASPGHAN Annual Meeting.

CPNP committee REPORTS

NASPGHAN Nutrition Committee

CPNP Rep: Carmyn Thompson, RD, LDN

The Nutrition Committee has formed a subcommittee to address the current formula shortage. Mead Johnson has offered a grant for a nutrition webinar, and the Nutrition Committee has also asked CPNP to partner on this project.

The webinar entitled, *The How, What and If's About Early Childhood Growth, Part 1* will air on August 24th. Look for registration details coming soon. The moderator is Timothy Sentongo, MD, Chair of the Nutrition Committee.

NASPGHAN Public Education Committee

CPNP Reps: Wendy Elverson, RD, CSP, LDN
Sharon Weston, MS, RD, CSP, LDN

Please take advantage of familiarizing yourself with the GIKids site and the many wonderful handouts that are available on GIKids.org! Take note that the Committee has been working hard to update materials on the site, and all will be available in English, Spanish and French. If you have any suggestions for additional nutrition related handouts to improve GIKids.org, please reach out to Wendy (Wendy.Elverson@childrens.harvard.edu) or Sharon (Sharon.weston@childrens.harvard.edu).

NASPGHAN Public Affairs/Advocacy Committee

CPNP Rep: Sally Schwartz, BS, RD, CSP, LDN

The Public Affairs and Advocacy Committee has been focusing effort on the infant formula crisis. On May 25, 2022, NASPGHAN submitted testimony about the infant formula crisis to the Appropriations Committee's Subcommittee on Agriculture.

A virtual briefing on the formula shortage with NASPGHAN and the White House also occurred June 23 at 7 PM ET. The briefing provided the latest updates on infant formula supply, medical guidance for providers and practitioners, and an overview of important resources for medical professionals, families, and community members.

CPNP and NASPGHAN members continue to work on improving access to medical nutrition therapy via the Medical Nutrition Equity Act. CPNP members are urged to contact their members of Congress and to ask them to cosponsor the Medical Nutrition Equity Act (MNEA) S. 2013, H.R. 3783, which will provide a cost-effective lifeline to Americans with digestive and metabolic diseases.

NASPGHAN Technology Committee

CPNP Rep: Nicole Martin, RD, CSP, CD

The NASPGHAN Website Subcommittee wants your input on how you use our websites (NASPGHAN.org, NASPGHAN and CPNP members pages, LearnOnline, GIKids, etc.), what you like about them and how they can be further improved. Please complete this brief survey to share your feedback to help the subcommittee prioritize future changes and upgrades to the websites.

NOMINATIONS FOR THE CPNP 2022 ELECTION

It is never too early to start thinking about the future. The call for nominations for the CPNP 2022 election is June 15 - July 15, 2022.

OPEN CHAIRS:

PRESIDENT-ELECT
PROGRAM CHAIR
MEDIA CHAIR
COMMUNICATIONS CHAIR

Terms will start at the end of the business meeting during the Annual Meeting in October.

Nominations will close July 15, 2022.

Please see our webpage for descriptions of the open positions. Please reach out to us directly at (cpnp.naspghan@gmail.com) if you have any questions.

member PROFILE

VANESSA WEISBROD

Vanessa Weisbrod is the Education Director of the Boston Children's Hospital Celiac Disease Program where she works to build a robust community engagement and education program.

Vanessa comes to BCH after 12 years as the Director of the Celiac Disease Program at Children's National Hospital in Washington, DC, where she led the effort to create national recommendations for managing children with celiac disease in learning environments and research looking at cross contact with gluten in shared kitchens and schools. She developed innovative approaches to education that methodically allowed families to successfully adapt to the gluten-free diet, including producing a series of cooking and nutrition videos, building an interactive digital app for celiac education, hosting a bi-monthly podcast and managing live and web-based educational forums.

Vanessa sits on the executive committee of the Harvard Medical School Celiac Research Program and the board of the Celiac Kids Connection. She is also on the Executive Council for the Society for the Study of Celiac Disease. She has authored four gluten-free cookbooks and whole heartedly loves gluten-free food. Vanessa was diagnosed with celiac disease in 2004 and her son was diagnosed in 2016 when he was three years old.

What are your current interests in the GI field?

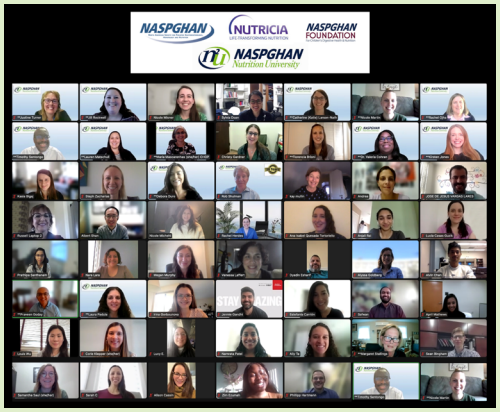
I am passionate about developing innovative approaches to patient and family education, particularly using TikTok as an example of micro learning for celiac disease and gluten-free diet education. Check out our @BostonChildrensCeliac channel. We have to meet adolescents where they are. If the platform we're using to educate is "cool," then hopefully they will be more likely to use it! I'm also very interested in better understanding and supporting families with celiac disease who are food insecure. I've been on the Operational Planning Committee for our new Boston Children's Hospital food pantry where we are now helping to provide food to 122 families with celiac disease. We all know how expensive the gluten-free diet is, so we have to make sure that we're helping families access food who really need it.

Describe your involvement in NASPGHAN and CPNP:

I've been a part of the Celiac Disease SIG since it first began and have loved working with CPNP on a nutrition pearl and newsletter article. I hope to do more of these in the future!

Name something that relates to what CPNP means to you, and what you would recommend to other members about taking advantage of what CPNP has to offer:

I love being a part of CPNP because they are so many wonderful individuals who really care about improving the lives of patient families and are excited to learn every single day. It's such a warm and vibrant community. My advice is that even if you have the craziest idea, don't be afraid to share it . . . there is likely someone who will be equally passionate about it to collaborate with!



N²U SUMMARY

NICOLE MISNER, MS, RDN

It was a great privilege to be selected and participate in the 2022 N²U NASPGHAN Foundation Nutrition University, which was held April 8-10, 2022 as a virtual conference. A total of 10 CPNP members were chosen to attend this year. The course highlighted the interdisciplinary model within pediatric gastroenterology with expert faculty comprised of both pediatric gastroenterologists and dietitians. Several dietitians were faculty at this year's event. They included Florencia Brioni, MS, RD; Alison Cassin, MS, RD, CSP, LP; Kirsten Jones, RD, CSP, LD; Nicole Martin, RD, CSP, CD; Lauren Matschull, MBA, RD, CD, CNS, Laura Padula, MS, RD, CSP, LDN, and Jill Rockwell, RD, CSP, LD, CNSC, CCTD. The syllabus provided specialized nutrition education in critical areas associated with practice in gastroenterology. Topics ranged from nutritional management of allergic GI diseases and IBD, growth failure in liver disease, cystic fibrosis, to the latest research in the microbiome. The small group case-based presentations allowed for "hot" topic discussions among participants and faculty, and the small group consisting of only dietitians fostered unique professional connections. I left the conference with a stronger nutritional foundation and felt both inspired and grateful to be a part of the pediatric gastroenterology community.

interested in VOLUNTEERING?

CPNP members sit on many of the NASPGHAN Committees and we have several openings coming up term starting after the Annual Meeting in October.

Eligibility Requirements: Full member in good standing (dues paid in full).

Terms for committee members: Three years starting after NASPGHAN/ CPNP/APGNN Annual Meeting

RESPONSIBILITIES

- Commit the time and effort required
- Work collaboratively for CPNP
- Communicate effectively by email
- Perform committee assignments in a timely fashion; if committee members are unable to complete assignments, they are responsible for identifying a suitable replacement for their duties
- Participate on committee conference calls in a frequency as designated by committee chair
- Help develop and execute the committee action plans
- Have a passion for the mission

OPEN NASPGHAN COMMITTEES

CCQ: Clinical Care & Quality Committee—
The committee seeks ways to address pertinent issues that affect pediatric GI practice in both the institution and community-based settings with an emphasis on quality and clinical care issues. Included in this effort are: novel projects and research initiatives to gauge and improve current clinical practice and quality of care; reviewing and guiding the development of societal manuscripts including clinical guidelines and position papers; and supporting the educational process by reviewing vignettes for the Annual Meeting and providing MOC Part 2 materials.

Neurogastroenterology & Motility Committee—
This committee is charged with promoting education of its members, health care providers and the public and fostering research in the area of Neurogastroenterology and Motility, which will translate into quality care for the patients and families being served. The Committee will help develop standards of care practice guidelines and quality improvement goals.

Hepatology Committee—
This committee focuses on promoting education, research, quality care and advocacy in the field of pediatric hepatology and transplant hepatology. In its educational role, the Committee is responsible for symposia planning at the annual Liver and Digestive Diseases Week meetings. Its members also participate in updates of clinical guidelines and position statements on matters related to liver disease and liver transplantation in children. The Committee also identifies areas in pediatric hepatology and liver transplantation, and working with the Public Affairs and Advocacy Committee, advocates on positions it believes will benefit children with liver disease.

Pancreas Committee—
The overall purpose of this committee is to promote the field of pediatric pancreatology. Its goals involve the expansion and dissemination of knowledge about pancreatic disorders, improvement of care for children suffering from pancreatic problems, advocacy for these children and their families, as well as promoting and supporting research within the realm of pancreatology. The Committee liaises with other NASPGHAN committees (in particular Endoscopy & Procedures, Training, Public Affairs & Advocacy, and Public Education Committees) to address common overlapping goals, and aims to similarly create links with external organizations. It is hoped that through the development of educational materials for the public and physicians, involvement in continuing medical education endeavors, and support of basic/ translational/ and clinical research, that the overall care and quality of life of children with pancreatic disorders will improve.

Public Education Committee—
The committee is responsible for developing, reviewing and publishing educational materials for the public (patients, families, caregivers). Content development for NASPGHAN's public education website, GIKids.org, is our top priority. Committee members participate in writing, editing and developing topic articles and audiovisual content. Members collaborate with the Technology Committee regarding content governance, the designated Webmaster/Internet service provider regarding social media content, and other NASPGHAN committees (e.g. Nutrition, Hepatology, Motility) for specialized content.

hot {topic}

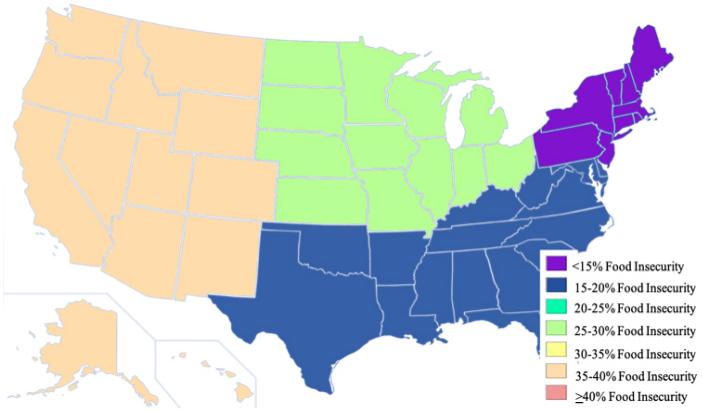
Food Insecurity in Pediatric Celiac Disease

Vanessa Weisbrod and Dr. Nan Du
Boston Children's Hospital Celiac Disease Program

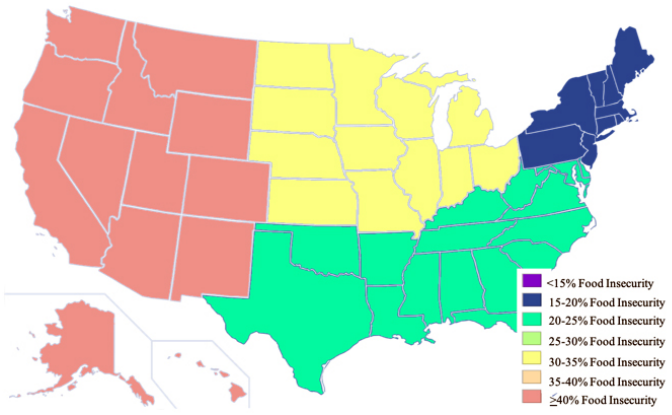
The U.S. Department of Agriculture defines food insecurity as a lack of consistent access to enough food for an active, healthy life. Feeding America projects that 42 million people (1 in 8), including 13 million children (1 in 6), experienced food insecurity in 2021.

A recent study from our team at Boston Children's Hospital found that 24% of pediatric celiac patients experienced general food insecurity during the COVID-19 pandemic and that when asked specifically about gluten-free food, 27% of the patients screened positive for food insecurity. Both food insecurity and gluten-free food insecurity increased during the pandemic. Approximately 1 in 20 households were food secure but screened positive for gluten-free food insecurity. Another study found that one in 6 patients with celiac disease are food insecure.

FOOD INSECURITY DISTRIBUTION BY REGION IN THE U.S.



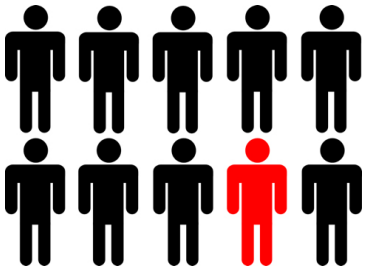
GLUTEN FREE FOOD INSECURITY DISTRIBUTION BY CENSUS REGION IN THE U.S.



Where is this food insecurity coming from? We know that processed gluten-free foods are consistently more expensive than their gluten-containing counterparts ranging from 4% to over 800% more expensive. In addition to costing more, the nutritional content of gluten-free food items is often poorer than conventional food items with added fats, sugar, and salt. This dramatic increase in food costs can lead to significant hardship for families who must eat gluten-free at every meal. Furthermore, state and federal food assistance programs (i.e., SNAP, WIC) do not consider the steep increased cost of gluten-free foods, and in some cases require that bread and cereal products be made from whole wheat, a factor that would cause serious harm to a patient with celiac disease.

Additionally, free and reduced breakfast and lunch programs that offer food to children at school do not reimburse schools for the increased cost of gluten-free food. This often leaves children with celiac disease unable to access these federal assistance programs that are designed to feed some of the nation's most vulnerable children.

How does food insecurity impact a patient's ability to adhere to a strict gluten-free diet? In our Boston Children's Hospital study, one in 10 households with a child on a gluten-free diet that was food insecure, reported eating gluten due to limitations on accessing gluten-free foods. Intentional gluten ingestion doubled during pandemic and the odds of intentional gluten ingestion increased if multiple household members were on gluten-free diet and if they screened positive for food insecurity. Another study from the University of Calgary found that less than one quarter of food insecure celiac patients adhered to a gluten-free diet.



So, what can you do to help families with celiac disease who are food insecure? It all starts with screening. In our Boston Children's Hospital Celiac Clinic, we use the Hunger Vital Sign (HVS) Screener to screen for food insecurity. This is a two-question screening tool. You can also modify it to include the term "gluten-free." You can add this screener to a pre-visit survey, clinical assistant check-in, physician or dietitian assessment, or enrollment in hospital-based support group.

> "Within the past 12 months we worried whether our [gluten-free] food would run out before we got money to buy more."

> "Within the past 12 months the [gluten-free] food we bought just didn't last and we didn't have money to get more."

The options for replying to the HVS screener include *often true, sometimes true* or *never true*. A response of *never true* would be a negative screen. While this patient is not positive for food insecurity today, we know that food security status can change rapidly depending on social situations and jobs, so please continue to screen at each subsequent clinic visit. A response of *often true* or *sometimes true* is considered a positive screen. For patients who screen positive, they should be referred to social work and offered food access resources.

Hot Topic continues . . .

While supporting a food insecure family may seem overwhelming at first, there are simple resources your clinic can put together to support families with celiac disease who are struggling to access food.

First, enroll the child in school food programs that offer free breakfast and lunches. These programs are funded by state and federal resources and are required by law to provide gluten-free foods to students with celiac disease. Schools should provide gluten-free breakfast and lunch options that reasonably meet the same nutritional content as meals served to other students — we want to see them offered a protein, dairy, grain, fruit, and vegetable.

Next, work on creating a list of food pantries in your area that regularly stock gluten-free foods. It's helpful to form a relationship with these pantries so you can let them know when a family may need food. The National Celiac Association Feeding Gluten-Free program has a great list of food pantries around the country that stock gluten-free foods.

Ask your social work team to help enroll the family in federal and state food assistance programs like SNAP and WIC. While gluten-free options are challenging in these programs, families can utilize the benefits for fresh fruits and vegetables, dairy, and proteins.

Finally, consider reaching out to local grocery stores to donate gift cards to help food insecure families purchase foods and work with your hospital philanthropy team to raise funds to enroll patients in food support programs like the Food Equality Initiative. The Food Equality Initiative is a program where clinicians can refer patients to get monthly boxes of food that meet the requirements of their special dietary needs. There is a cost for every patient referral, so this option typically requires a donor to offset the costs.

Our Celiac Program at Boston Children's Hospital is passionate about working to better understand and support the needs of food insecure families with a child with celiac disease. If you or your Program are interested in working with us, please reach out to us at (celiac@childrens.harvard.edu).

References:

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3—Panagiotou S, Kontogianni MD. The economic burden of gluten-free products and gluten-free diet: a cost estimation analysis in Greece. J Hum Nutr Diet. 2017 Dec; 30 (6):746-752. doi: 10.1111/jhn.12477. Epub 2017 May 8. PMID: 28480510.

4—Singh J, Whelan K. Limited availability and higher cost of gluten-free foods. J Hum Nutr Diet. 2011 Oct; 24 (5):479-86. doi: 10.1111/j.1365-277X.2011.01160.x. Epub 2011 May 24. PMID: 21605198.

5—Allen B, Orfila C. The Availability and Nutritional Adequacy of Gluten-Free Bread and Pasta. Nutrients. 2018 Sep 25;10(10):1370. doi: 10.3390/nu10101370. PMID: 30257431; PMCID: PMC6213709.

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7—Taetzsch A, Das SK, Brown C, Krauss A, Silver RE, Roberts SB. Are Gluten-Free Diets More Nutritious? An Evaluation of Self-Selected and Recommended Gluten-Free and Gluten-Containing Dietary Patterns. Nutrients. 2018 Dec 3; 10(12):1881. doi: 10.3390/nu10121881. PMID: 30513876; PMCID: PMC6317051.

hot {topic}

Formula Recall: RD Response

Lauren Jalali, MS, RD, LDN

Background

In February 2022, Abbott Nutrition issued a voluntary recall of their powdered formulas, including Similac, Alimentum, and Elecare, which were produced at their manufacturing plant in Sturgis, Michigan. The facility also stopped the production of formula entirely. The recall and consequent shutdown were in response to four infant illnesses, which included two fatalities, associated with Cronobacter infections in infants who had consumed formula originating from the Sturgis plant[1].

Impact and Scope

The recall resulted in an acute and severe formula shortage and strained an already struggling formula supply system. The infant formula market in the United States is very small: 98% of infant formula sold in the United States is manufactured domestically[2]. Abbott is one of four infant formula manufacturers of standard and extensively hydrolyzed formulas (Reckitt-Mead Johnson, Nestlé, Perrigo) and one of four amino-acid based formula manufacturers (Reckitt-Mead Johnson, Nestle, Nutricia). Additionally, Abbott represents 40% of the infant formula market, and their Sturgis, MI plant makes about 40% of that production[3], meaning recall of their specific product results in a huge vacuum of formula availability. In early May, out-of-stock rates nationally were at 43%, with over half of infant formula sold out in some states[4]. This does not include the unavailability rates of elemental and metabolic formulas, where available alternatives are even more limited.

Additionally, Abbott is the main contracted formula provider in many states to programs providing supplemental support and benefits to vulnerable populations, including the Special Supplemental Nutrition Program for Women, Infants and Children (WIC). WIC is the largest purchaser of infant formula in the country, and about 50% of patients purchasing formula do so using WIC benefits[4].

Loss of access to an essential source of nutrition has led to increased food insecurity for vulnerable pediatric populations, including infants as well as children with unique medical conditions. Infants require formula or breast milk exclusively for the first 6 months of life, and continue to require formula or breast milk as well as complementary foods up until 12 months of life. For premature infants, adjusting for their corrected age (for example, an infant born 1.5 months early will reach 12 months corrected age at 13.5 months chronological age) by definition extends the window of a requirement for formula. Additionally, patients on enteral nutrition support require their formula supply to sustain adequate nutrition intake and, depending on medical conditions and unique nutrition requirements, may have limited alternatives to use in case of shortages.

Hot Topic continues . . .

Clinical Risks

Insufficient formula supply leads to clinical risks of inadequate nutrition, including weight loss or inadequate weight gain, new or worsened malnutrition, dehydration, allergic reactions, and intolerances.

Additionally, families desperate for a solution may turn to formula alternatives that compromise patient safety [5-7]. These unsafe practices may include offering formulas containing allergens, watering-down formulas, using oral rehydration solution, homemade baby formulas, or contraband formulas (not approved for use in the United States by the FDA), or prolonged use of whole cow's milk or non-dairy milk, instead of infant formulas. According to the American Academy of Pediatrics (AAP), whole cow's milk can be substituted in infants 6-12 months of age if formula is unavailable, but not for longer than 1 week.

The Registered Dietitian (RD)'s Role and Response

Registered dietitians are very involved in care for patients on specialty formulas due to their nutritional complexity, and are experts in guiding patients to choose an appropriate formula substitution when their formula is no longer available.

Many patients with complex medical needs or requiring enteral nutrition support are also using a custom recipe for formula made to a specific concentration (above 20kcal/oz for infant formulas, above or below 30 kcal/oz for junior formulas). Because different formulas have different specifications (for example, scoop size, formula weight, and displacement), custom recipes are not always interchangeable. RDs provide patients with new recipes for each formula change to make the appropriate calorie concentration.

Many patients have been unable to obtain the correct type or amount of formula from their medical supply (DME) companies, through WIC, or at retail. RDs can help to identify alternative sources of bridge samples from patients' PCP, GI, specialty clinics, or representatives of formula makers. The RD also advises DME companies on appropriate formula substitutions, if their standard formula is unavailable.

Registered Dietitians take on the role of educating families and, at times, other health care professionals regarding appropriate, safe formula alternatives and which substitutions to avoid. If the patient is changing formulas, changing the caloric concentration of their formula, or starting a home blend, the RD develops a new regimen for the alternative formula and, if applicable, creates a home blended recipe, for that individual.

In some practices, even though registered dietitians are not prescribers, they may calculate and provide the details of formula prescriptions based on patients' recommended intake and caloric density of formula to advise the prescriber on the correct monthly allotment. With each formula change, the RD may need to provide updated information on the new prescription (see Supplemental Information: Example Prescription Grid).

Due to the level of involvement in several steps of patient care for patients on specialized formula regimens, the workload of Registered Dietitians and other healthcare workers involved in this process has dramatically increased with the increase in demand for formula alternatives [5]. This, in turn, takes time away from providing direct patient care and other patient care activities.

Registered Dietitians also carry a strong and important voice in public health advocacy. The Academy for Nutrition and Dietetics (AND), like NASPGHAN and other medical professional organizations, promotes public policy and advocacy efforts related to nutrition. AND representatives from their Pediatric Nutrition Practice Group recently met with Congress for a hearing on the infant formula shortage. This included stories collected from RDs across the country and presented to Congress to highlight the impact of the formula shortage on constituents[8].

Prevention

There are several opportunities for legislation and public health initiatives that may alleviate a future major shortage in response to a formula recall. These include: diversified brands and multiple facilities that produce infant formula and specialty formulas; expanding WIC access to alternative brands of formula in the event of a shortage or recall; public education on equivalent formula alternatives for various types and categories; legislation establishing an emergency protocol in the event of future shortages/recalls, and increased support for enhanced and prolonged breastfeeding[4,5].

In practice, clinicians may consider increasing variety and diversity in the brand of formulas recommended to patients as appropriate. For patients on hypoallergenic and elemental formulas, practitioners may also consider the length of time specialized formulas may be required. It may be appropriate to re-introduce trials of less specialty formulas or blended formulas to increase the variety of intake and reduce dependence on a sole nutrition source. This should be a collaborative effort between the formula prescriber and the RD to ensure an appropriate new regimen is identified.

Tips for Managing the Formula Crisis

Prescriptions and DME (formula supply) Companies

- Consider prescriptions written for ideal formula "or equivalent alternative"
  - For patients on public health insurance, some states have waived requirement for a new prior-authorization with each formula change
- Seek out DME companies locally who are willing to fill oral intake prescriptions, as many companies prioritize those who require formula for enteral nutrition support
- Collaborate with DME companies to understand which formulas they are contracted to carry and dispense
- See supplemental information: Example Formula Prescription Grid, for straightforward prescribing

Alternatives to consider for some patients on formula

- Equivalent formula from an alternative brand. Several organizations, including NASPGHAN, have a resource for this (see Supplemental Information).
- Blenderized formula or home blended formula

Hot Topic continues . . .

- Trial plant-based (pea protein) formula for older patients on elemental, hypoallergenic formulas
- Re-trial standard or partially-hydrolyzed formulas if safe to do so for those on elemental and extensively hydrolyzed/ hypoallergenic formulas
- Modified formula concentration or concentrate with a caloric modifier instead of formula
- Store-brand infant formula for those on standard infant formulas or partially-hydrolyzed formulas

Supplemental Information

Note: Due to the nature of frequent changes in formula composition as well as the availability of formulas (domestic and international), the reference tools for substitutions are ever-changing and require frequent updating.

- Appendix A: Example Formula Prescription Grid

Prescription/Formula Name	
Route of treatment (PO, NG, NJ, GT, JT, PO/PG)	
Length of need (months)	
Number of monthly refills	
Volume/fluid oz. per day	
Calories per day	
Calories per fluid oz.	
Units per day	
Quantity per month	
% of nutrition from formula	
Type of formula (powder, ready-to-use, concentrate)	
DME provider, if known	
Past trials, if any	

- NASPGHAN Tools for HCPs Managing Infants and Children Affected by Formula Recall

References:

1—FDA Investigation of Cronobacter Infections: Powdered Infant Formula (February 2022). Accessed June 2022.

2—FACT SHEET: President Biden Announces Additional Steps to Address Formula Shortage. May 12, 2022. Accessed June 2022.

3—Kimball S. Abbott baby formula plant had "egregiously unsanitary" conditions, FDA chief says in scathing testimony to Congress. CNBC, May 25, 2022. Accessed June 2022.

4—Doherty T, Coutsoudis A, McCoy D, Lake L, Pereira-Kotze C, Goldhagen J and Kroon M. Is the US infant formula shortage an avoidable crisis? The Lancet. 2022. doi: 10.1016/ S0140-6736(22)00984-9. Epub ahead of print.

5—Abrams SA, Duggan CP. Infant and child formula shortages: Now is the time to prevent recurrences. Am J Clin Nutr. 2022 May 17;nqac149. doi: 10.1093/ajcn/nqac149. Online ahead of print. PMID: 35580593.

6—Infant/Pediatric Formula Information Pertaining to Abbott Recall of Formula and Sporadic Scarcity of Formula Products. Accessed June 2022.

Hi members! We're looking for members who want to get more involved with CPNP!

HOT TOPIC ARTICLES

If you have a topic you would like to share in one of the upcoming newsletters, please contact Sharon Weston at (sharon.weston@childrens.harvard.edu)

NUTRITION PEARLS

If you would like to be an author of one of our Nutrition Pearls, please contact Bailey Koch to get started. (bailey@atlantapediatricnutrition.com)