



Ketogenic Diets in the Pandemic

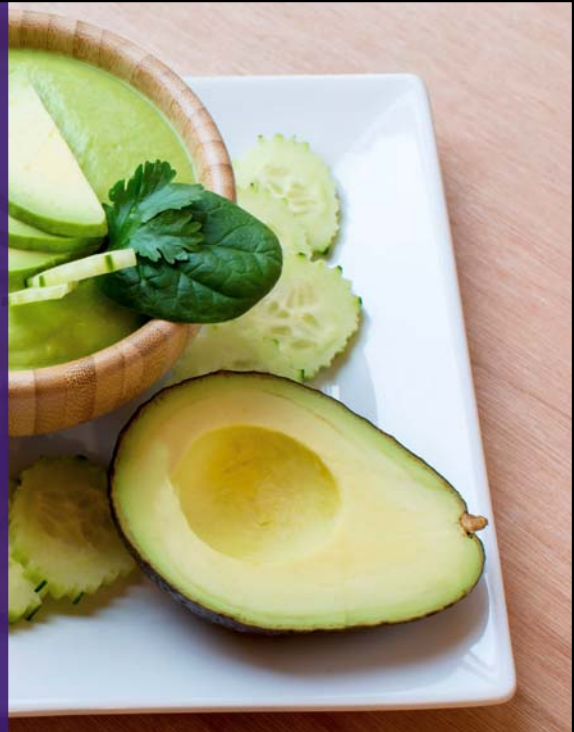
Past Ideas and Future Directions

December 9, 2020

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Disclosures



- ❑ Eric Kossoff: Consultant to Atkins Nutritionals, Nutricia, NeuroPace, Dr. Schar, Vitaflo, Aquestive, Bloom Science; DSMB Greenwich, BioPharm, NIH, Royalties: Springer, UpToDate, Oxford
- ❑ Stacey Bessone: Consultant to Nutricia
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- ❑ ***None pose any conflict of interest for this presentation***

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Learning Objectives



Recognize the challenges of providing ketogenic diet care in the COVID-19 pandemic

Hear about recently published inpatient and outpatient solutions

Learn about a published survey of international centers and their response to COVID-19 using the diet

Attendees will share their own thoughts and ideas!

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KD in the time of COVID-19

Zahava Turner, RD, CSP, LDN

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Preparation



- ✓ Think about **what is available at the hospital and your daily routine**
- ✓ **Bring tools and materials home**
 - ✓ Scale, formula, supplies that you show the family
- ✓ **List sent to families** on what items should be purchased
- ✓ **Prepare foods in your house** that the hospital would normally send for the families
 - ✓ Educate the family how to prepare them as meals in their hours

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Pre-Keto Shopping list



Essentials

Fats:

- Heavy Whipping Cream
- Butter
- Mayonnaise
- Oil (any kind of oil – vegetable, canola, olive, coconut, ghee)

Protein

- Eggs
- Bacon
- Chicken, beef, pork, fish, shellfish (any of these products)
- Tuna fish

Fruits and Vegetables

- Fresh, frozen or canned

Non-essential (but helpful to have)

Snack Foods:

- BabyBel® cheese
- Guacamole snack packs
- Pork rind
- Beef jerk
- Cheese crisps

Nuts

- Raw whole nuts
- Nut Flours
- Nut Butters
- Shelf Stable nut milks

You don't need to buy everything on the list ... know what your child likes in these categories

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Family to pick up of keto stuff before starting the diet

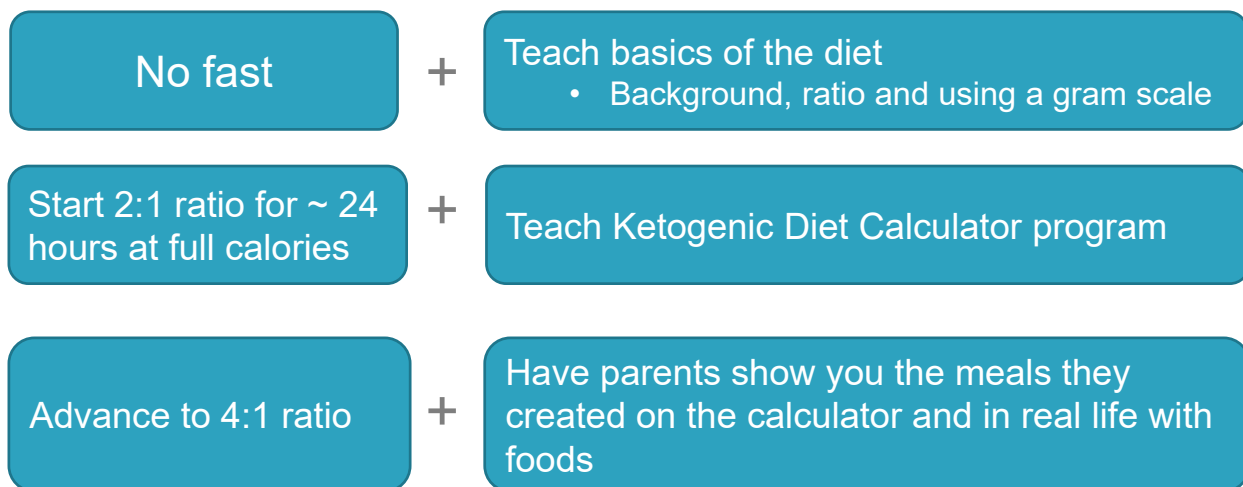


- Scale
- Book
- DVD
- Vitamins
- KetoStix®

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Overview of Initiation




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Schedule		NLC NUTRICIA LEARNING CENTER
DAY 1		DAY 2
9 am	Zoom lecture 1 – Introduction to Keto <ul style="list-style-type: none"> Led by attending, dietitian present Child does not fast. Regular breakfast. 	Zoom televisit – no lecture <ul style="list-style-type: none"> Led by attending (also prescribes CytraK) Family makes 2:1 ketogenic breakfast and checks urine ketones on own prior to visit
11 am	Zoom lecture 2 - Diet basics and how to weigh/measure foods <ul style="list-style-type: none"> Led by dietitian Family will make 2:1 ketogenic lunch with Zahava supervising. Full calories. 	Zoom lecture 4 – Parent support <ul style="list-style-type: none"> Led by dietitian Family makes 4:1 set recipe lunch
1 pm	Zoom Lecture 3 – Handling sickness on the ketogenic diet, checking ketones. <ul style="list-style-type: none"> Led by Attending or RN 	Zoom Lecture 5 - Using KetoDietCalculator and other computer recipe sites <ul style="list-style-type: none"> Led by dietitian
5 pm	Family uses recipe for 2:1 ketogenic diet dinner. Dietitian assistance as needed	Family can either use computer program or the set 4:1 ketogenic dinner recipe to make dinner. Quick call from attending or RN to check in.

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Schedule



DAY 3

9 am

Zoom Televisit – no lecture

- Led by attending and dietitian
- Exam and ketones.
- Family makes breakfast using KetoDietCalculator (preferred) or 4:1 breakfast from recipe.

DAY 4


Zoom Televisit – no lecture

- Led by attending MD and dietitian

If family is completely formula-fed, they can skip lectures 4 and 5

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Pros and Cons Telemedicine Initiation



Pros	Cons
<ul style="list-style-type: none">□ Can see the foods they have in their house<ul style="list-style-type: none">■ Appliances, tools, kitchen gadgets, etc. they actually have□ Patient more willing to eat the foods they are familiar with versus hospital prepared foods□ Education can be flexible based on family and dietitian's schedule	<ul style="list-style-type: none">□ Internet issues□ Difficult to establish personal connection□ Hard to feel the team approach

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Urgent Inpatient Initiation During COVID



Goal: Education and Diet Tolerance

- ▣ Review admission protocols and see what can be eliminated
- ▣ No fast
- ▣ We did ½ strength calories and then full calories
- ▣ Can do 2:1 and then 4:1
- ▣ Close follow up once home via Zoom

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MAD in the Time of COVID-19

Stacey K. Bessone, RDN, LD/N

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JHACH Telehealth



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Initial Visit - MAD teaching



- For social distancing we used conference room
- We each had our own computer
- Prior to visit, reviewed needs for the patient (labs, scripts, etc)

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Telehealth Initial Visit



Viewing the patient - surroundings, family interactions

Email handouts - review with patient

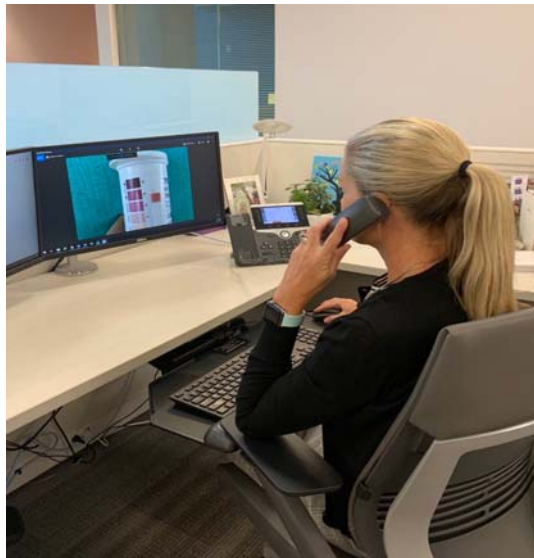
Label reading - find food item to review

Engage with tech savvy patients



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JHACH Telehealth



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Telehealth Follow Up Visit



- If possible - obtain pictures of weight and urine ketone testing strips
- Review diet understanding
Ask questions about meals?



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Telehealth Follow-Up Visit



- Assess compliance
Do they have a food record?
Are they eating the right foods?
- Review tips/discuss obstacles
Discuss adding fat to meals
Address any food shortage situations/access

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Follow-Up



Used some phone time for education (not on screen)



Follow-up emails required more precise instructions

Our teenaged patients were more engaged



Able to do a visit in 30 minutes vs 1-hour



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RD – What I learned



- ✓ Require **pictures of weight** and, if possible, **lengths/heights** for all patients
- ✓ **Email handouts** days before appointment
- ✓ **Require more visual of the patient** for NFPE and pictures of any concerns

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JHACH - What is happening now



In person visits
for all new
patients

In person visits
unless parent
requests
telemedicine visit

Initiations are 2
patients (at most) at
a time.

No in person group
classes

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JHACH - What is happening now



- Grant obtained to help with supplies

COVID-19 Program/Project Background



During the COVID-19 pandemic, patients with intractable epilepsy continue to need ketogenic diet therapy after multiple medications did not control their seizures. These patients require hospital admission and must come with a list of supplies to start the ketogenic diet. This includes a gram scale, urine ketone testing strips, cotton balls, vitamin and mineral supplements and additional food items that may be on the diet that were previously not purchased in the home.

I propose a ketogenic diet initiation kit that would include these items. Patients are not able to go to multiple store fronts to obtain all these supplies. Also, many online orders are out of stock or have delayed delivery such as ordering the scale to measure foods. Many families are experiencing financial hardships due to unemployment and reduced working hours for hourly employees. Families also face limited childcare and risk virus exposure by having to take their children out to shop for these items.

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This ketogenic diet kit would provide assistance not only financially, but also help with limiting exposure and physical distancing

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Keto Diet Follow-up in the time of COVID-19

Eric H. Kossoff, MD

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Keto Follow-up Clinic by Zoom



Changed to a Zoom-based outpatient protocol

- Patients initially seen every hour then reduced to 45 minutes
- Parents emailed in advance for understanding
- Group discussions (with "Pre" meetings 2-3 minutes in the Zoom room before admitting the families)
- Neurologist run and notes documented on 2nd screen
- Unlimited attendance

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Hi!

Zahava, Meghan and I are looking forward to seeing XXXX in VIRTUAL ZOOM keto clinic Tuesday 7/14.

Just wanted to make sure that works for you. Appt will be 12 pm.

1. Do not worry about getting labs in advance.
2. Make sure to get an updated height and weight on a scale and measure.
3. Keep your home or cellphone on as we may call you before to make sure you're ready and connect.

Here is the link:

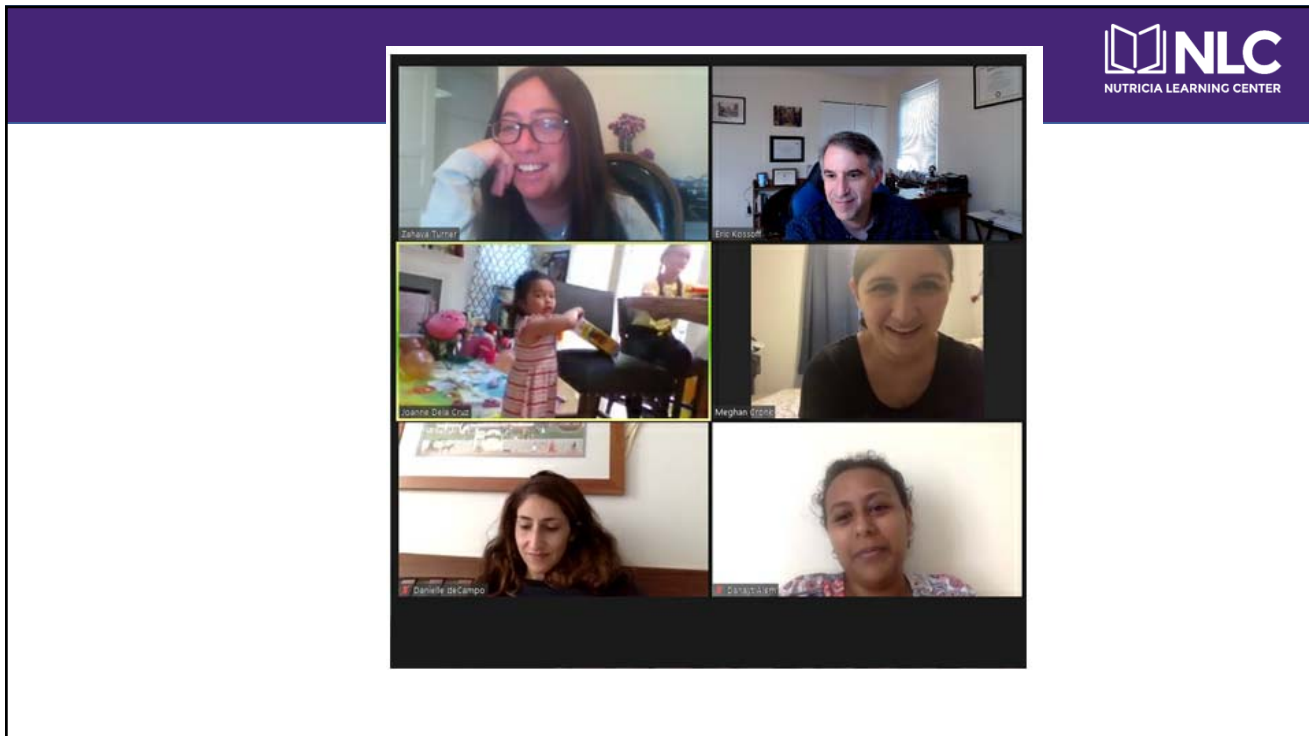
Join Zoom Meeting
<https://us02web.zoom.us/j/XXXXXXXXXXXX>

(ignore any other link sent in MyChart)

The appointment is 12pm
Email me back to confirm.


Thanks!
Eric & Zahava & Meghan

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August 2020



- Slowly returned back to in-person for clinic
 - No option for routine telemedicine offered to avoid confusion
- Full PPE and face shields; staff cleaning rooms; 1 parent per child; 2 rooms
- As clinic has become busier, longer days and 1-hour appointments evolved
- Limited numbers/room

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December 2020



- With the recent surge, we have returned to virtual clinic again
- 45-minute appointments; Zoom-based
- Plan to return to in-person March 2021

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Pros and Cons – Virtual Keto Clinic



Pros

- Unlimited visitors
- Unlimited parents
- Can see home environment
- Save travel/parking
- No check-in/out time
- Potential to see patients from farther away
- Children with behavioral issues

Cons

- Unable to physically examine
- Height/weight imprecise
- Lose the “face-to-face”
- Big decisions tough
- Distracted by your home situation/WiFi
- Lots of follow-up emails

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Wirrell survey



- Multicenter study just published in *Journal of Child Neurology* November 2020
 - Care delivery for children with epilepsy during COVID-19 pandemic: an international survey of clinicians
- April 10-24, 2020
- 212 child neurologists responded
 - 46 US pediatric epilepsy centers (~32% of 144)
 - 39 responded to the ketogenic diet questions

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Wirrell survey: Results



92.3% reported an impact of COVID-19 on their ketogenic practice

Initiation

62-69% only could initiate for emergencies (either in person or virtual)

26-31% had to stop entirely

Only 2.9% able to do outpatient for any child

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Wirrell survey: Results



Follow-up clinics less affected

51% telemedicine only; 43% no change!

37/38 reported dietitians could do televisits

Labs

46% reduced frequency of surveillance labs

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Wirrell Conclusions



- *“sharply restricted...as a result, children who require dietary therapies are at risk of either being prescribed a potentially less-effective option (MAD or LGIT) or of suffering important adverse effects while treated at home”*
- *“Return to prepandemic standards of care should be a priority as epilepsy programs resume clinical operations”*

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Future



- Hybrid model for follow-up clinic?
 - Clear organization and scheduling required to ensure parents know where to go

- Perhaps even alternate visits over time?

- Either way, be flexible!

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Discussion!

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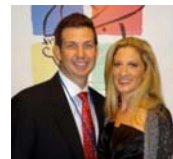





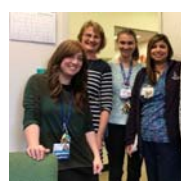












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