

Refsum Diet Webinar

Question & Answer Documented

Questions were submitted during and after the Refsum Diet Webinar held on July 24, 2020. Answers were provided during the webinar and further documented by Eleanor Baldwin and Sarah Firman the dieticians at the Guy's & St. Thomas Hospital after the webinar.

As stated in the webinar it is always important to consult directly with your dietitian and clinician who knows the details of your specific medical situation. They may have different recommendations for you.

General

- In a standard diet how many mg of phytanic acid is ingested in a day?**

For a person who does not have Refsum disease a typical diet may contain 50-100mg of phytanic acid per day. For a low phytanic acid diet a person would look to keep their phytanic acid intake below 10mg.

- Can you advise on carb fat protein daily ratio?**

The acceptable macronutrient distribution ranges for the general population are: carbohydrate 45%-65% of energy, protein 10%-35% of energy, and fat 20%-35% of energy. We would recommend aiming for the higher end of range for carbohydrates; however, this will depend on whether you have other medical conditions (such as diabetes) so would advise talking with your dietitian

- Is there a low phytanic acid diet and meal plan available?**

The updated diet guide and sample meal plan are available on the Global DARE Foundation site.

- If eating something higher would it show up in phytanic acid levels or store in tissue?**

Both

- Are you able to expand more about the biochemistry? If a person with Refsum eats foods higher in phytanic acid by accident (for example not being aware of ingredients) and is normally diet compliant would it be the case it is likely to be stored in tissue rather than be evident in increased phytanic acid levels for the next blood test? Assuming a person is not sick, has not lost weight or fasted what are the reasons that is phytanic acid that is released from the body's storage into our blood stream?**

Fatty tissues, like adipose, change and turnover which will release some phytanic acid into the blood. There are also other scenarios such as stress and hormonal changes which can affect the phytanic acid levels. Caffeine can also influence phytanic acid levels. If eating food that contains high phytanic acid would initially be shown in the blood but could later be stored, depending on the state the body is in (e.g. fasted versus fed).

- You mentioned that we do not know why some people's omega oxidation is more affected than others. Is there a way to measure a personal's level of omega oxidation?

A person's omega oxidation can vary under different circumstances and therefore a one-off measurement would not be able to provide further information on management

Nuts

- Should we choose nut free vegan products?

Overall nuts should be limited to a maximum 30g per week, we recommend choosing products that are within this limit

- I heard about/we thought nuts, especially walnuts, are not recommended. in the presentation you said walnut oil is a great source for omega 3 and 6. what is the recommendation here?

We are yet to analyze oils, so until further analysis would be best to use other sources of vegetable oils (e.g. canola or rapeseed oil)

- Are nut butters acceptable?

We need to analyze nuts, but until we have further information to limit nuts to 30g per week

- We are advised not to have almond milk, what about almond butter please?

We have not yet analyzed almond milk. Almond milk contains only a small number of almonds, but until we know more about the PA content we would recommend to have other milk alternatives such as soya or oat. Regarding almond butter - to limit all nuts to 30g/week including nut butters.

- As nuts have not been tested you have stated that you cannot provide a definitive answer in relation to vegan foods with nuts. However, you also mentioned that that based on your patient experience you have not seen higher phytanic acid levels from eating nuts. There are a lot of vegan foods which contain nut not just nut based milks. For example, cashew cheese and nut based yoghurts and ice creams. Often vegan food in restaurants will contain nuts. For example, a vegan ramen dish may have nuts. Would you have any concerns about the consumption of these type of foods where some type of nut would be an ingredient? Or would be better to choose nut free vegan foods until nuts are tested?

Overall nuts should be limited to a maximum of 30g per week, so we would recommend choosing products that are within this limit

Meat

- Is cut of meat relevant to phytanic acid levels in chicken or pork?

No

- **What is the effect of boiling or grilling a piece of meat on phytanic acid?**

No effect

- **What about casing on sausage that could be beef?**

Not likely to be a problem if only the casing of the sausage

- **You mentioned animal feeding practices. If for example a part of the diet of chicken may include grass would you have concerns about the phytanic acid level?**

No, the gut of a chicken means that it should not have a high phytanic acid content if it consumes grass

Diary Alternatives

- **Is soy or coconut yoghurt ok?**

Yes as far as we know, but planning to do further analysis

Spices / Oils

- **There are spices from the red pepper family such as chile, paprika and cayenne pepper. Given that you said it should be ok to have a small amount of red pepper say in a stir fry or salad does the same principle apply to using spices that are derived from the red pepper family?**

Likely to only use a small amount in a recipe. If using in small amounts (e.g. teaspoon) would be appropriate to have

- **Is olive oil acceptable, if we should avoid excess intakes of green olives?**

Olive oil has not been analyzed. Best to use other oils. Small amounts (e.g. teaspoon) would unlikely to be an issue

Seafood

- **Would farm raised Salmon be acceptable since it would not be fed or eat algae?**

Best to avoid as we cannot be sure of the phytanic acid content.

- **You mentioned that some seafood such as prawns are farmed. Have any patients at the Refsum clinic been eating farmed prawns? If so, have you noticed a change in their phytanic acid levels from eating farmed seafood?**

We have not seen any issues yet, but further analysis is needed to understand the impact of different farming on phytanic acid levels

Vegan Products

- **Can you explain why you would not recommend eating Quorn? Are there similar vegan products or brands you would suggest that we avoid? If so, can you explain why?**

We recommend limiting Quorn as we do not yet know about the phytanic acid content. As it is a fungal product there is potential that it might contain

Exercise

- **If only slow walking it about 3km per hour are there any issues walking over 45 mins?**

Recommend to eat before hand and if only 45 mins of slow walking, no need to eat during the walk. If going for >1 hour or higher intensity, would recommend carbohydrates during the exercise.

- **I understand that increase fitness may also mean a boost in metabolism which may result in phytanic acid being released from the body stores to blood. For those of us who have lost a lot fitness and mobility because of the rapid onset of the neurological symptoms of Refsum how would you suggest that we increase fitness? In addition to working with dietitian or exercise physiologist what type of expert could assist with boosting fitness levels safely?**

Exercise should be increased gradually whilst working with your dietitian and exercise physiologist to ensure adequate intake of carbohydrates to provide fuel and adequate protein to build lean muscle tissue.

- **What types of foods do you suggest before or after light exercise such as slow walking, stretching, weights, physiotherapy type exercises to improve strength and balance?**

A carbohydrate-based snack. If the goal is to build lean muscle, your snack should also include protein

- **Is there any dietary or exercise advice of Refsum related peripheral neuropathy in the legs and feet?**

Balance and core strength can be helpful such as Pilates or yoga. We would advise talking with a physiotherapist or using NHS online

Supplements

- **How much g from a omega-3rich oil would you suggest per day to get the dha/epa recommendation?**

Recommend aiming for the adequate intakes (AI) of omega 3 and omega 6 per day

Requires Further Research

- **What determines a person's level of omega oxidation?**

We do not know

- **Why is algae high in phytanic acid if in supplements? Isn't the issue the fermentation process when eaten by fish?**

We don't know for certain, but it would be the safest option to avoid

- **Is seaweed safe to eat?**

We do not know. This will need to be analyzed