

# Participant Comments Submitted Prior, During and After the XEROSTOMIA Externally-Led Patient Focused Drug Development (EL-PFDD) Meeting

Meeting Date: Thursday, 19 August 2021  
10 a.m. – 3 p.m. U.S. Eastern Time (Virtual Meeting)  
Report Date: 27 January 2022

This document accompanies and supports the “Voice of the Patient” report, available at [www.thancfoundation.org](http://www.thancfoundation.org), [www.swallowingdisorderfoundation.com](http://www.swallowingdisorderfoundation.com), [www.headandneck.org](http://www.headandneck.org), and [www.spohnc.org](http://www.spohnc.org).

Meeting co-hosted by Head and Neck Cancer Alliance (HNCA), the National Foundation of Swallowing Disorders (NFOSD), Support for People with Oral and Head and Neck Cancer (SPOHNC), and the THANC (Thyroid, Head and Neck Cancer) Foundation.



## Introduction and Context

The Xerostomia Externally-Led PFDD (EL-PFDD) meeting was co-hosted by Head and Neck Cancer Alliance (HNCA), the National Foundation of Swallowing Disorders (NFOSD), Support for People with Oral and Head and Neck Cancer (SPOHNC), and the THANC (Thyroid, Head and Neck Cancer) Foundation. This meeting was held to advance our collective mission to address the unique needs and challenges of patients living with xerostomia and their families, by helping to provide a deeper understanding of the symptoms and burdens associated with xerostomia in daily life, as well as the unmet needs of the community.

This EL-PFDD meeting was modeled after the work of the FDA's Patient-Focused Drug Development (PFDD) initiative. PFDD is a systematic way of gathering patient perspectives on their condition and on available treatments. The information gathered at the meeting is presented in this *Voice of the Patient* report. The information in this report will be used to guide drug and technology development and inform the FDA's benefit-risk evaluations when reviewing technologies and therapeutics to address xerostomia. The hope is that this information will ultimately catalyze significant improvements for the health and quality of life for people living with xerostomia.

An online comment submission portal was open for 30 days before and after the Xerostomia meeting in order to allow as many voices as possible to respond to the Meeting Discussion Questions, in Appendix 3 of the report. Comments that were submitted through the online portal are presented below in the order that they were submitted. The comments were edited slightly for grammar, spelling and punctuation. Respondents are identified by their first name and last initial only. Selected comments and excerpts were included in the *Voice of the Patient* report. Comments that did not address the Meeting Discussion Questions were removed. The final *Voice of the Patient* report, online comments, the meeting transcript and a recording of the meeting can be found at: [www.thancfoundation.org](http://www.thancfoundation.org), [www.swallowingdisorderfoundation.com](http://www.swallowingdisorderfoundation.com), [www.headandneck.org](http://www.headandneck.org), and [www.spoync.org](http://www.spoync.org).

**Judy**

I find that all of the special toothpastes, mouthwashes, fluoride gels, and other special preparations to put in the mouth are flavored with mint - fresh mint, gentle mint. The mint irritates my mouth causing my lips and the roof of my mouth to swell.

**Allen**

I have little saliva, full dentures. I have difficulty swallowing, biting, chewing, speaking, sucking. I also have no feeling in lower lip. I am coping well, having developed many survivor strategies. I have a lot to learn and also strategies to share.

**Belinda**

I'm most concerned about trying to keep my teeth and gums as healthy as possible for as long as possible. How can I keep my oral microbiome healthy with diminished salivary secretion? Water helps relieve dryness temporarily but seems like it rinses away what protective goodies I do manage to produce. Rinses and melts and chews I've tried don't seem to work for me.

**Daria**

I have mild dry mouth and I get parched at night. On my worst days, I am not able to quench my thirst and I feel as though I have a mild sore throat. My symptoms have slightly worsened over time. I can't say that dry mouth stops me from doing anything in particular, it just makes everyday life a bit more inconvenient. As I age, I fear it will worsen and impact my dental health.

I sometimes use XyliMelts. I like Biotène<sup>®</sup> toothpaste. I drink a lot of water. It would be ideal if there was a way to protect the saliva glands before radioactive iodine treatment.

**Michele**

I have struggled with xerostomia since my first radioactive iodine (RAI) treatment 13 years ago. My most significant symptoms are consistent dry mouth and bad breath. I must have water and/or mints with me at all times to address the dry mouth, and it makes public speaking very difficult. As I look forward to the future, my greatest concern is the impact that xerostomia will have on my dental health. An ideal treatment for xerostomia would be non-invasive and have few or no resulting side effects.

**Pat**

I always need a bottle of water within reach as my throat will close up, due to dryness. Now, I'm a senior and worry that I'll be alone and have a serious incident because of this. Eating out is a problem because I don't have enough saliva to swallow what I'm chewing. Food just packs around my molars. I'm constantly brushing my teeth. Upside is my teeth are VERY white.

**Ed**

Background. I'm a head and neck cancer survivor originally diagnosed with a base of tongue tumor in mid-2005. The next 2.5 years included 4 local recurrences that were treated with 36

IMRT radiation treatments, 6 surgeries (one a 12-hour salvage surgery), and 8 different chemo regimens (a regimen could last up to 8 months). I have very little saliva. While my discomfort with a low saliva volume is well treated with over-the-counter gels and mouthwash, dry mouth has been an invitation to rapid tooth decay.

Impact. Recognizing the impact of dry mouth promoting rapid tooth decay, I began having my teeth cleaned and fluoride applied every 2 months beginning over a decade ago. This significantly reduced the volume of cavities and allowed for an early diagnosis of other oral issues. Being in my late 60s I suspended my dental visits for 14 months due to the COVID-19 pandemic (February 2020 to April 2021). I suspected I would pay the price for this lapse in dental care and upon returning to my dentist in April 2021, my fears were well founded.

Specific impacts include the following:

- 1) A one-tooth Maryland bridge came loose due to the rotting of the tooth holding up one side of the bridge. The bridge was removed.
- 2) My dentist wanted to pull the rotted tooth, but I wanted to check with my cancer center first. The first available appointment was a month out and I took it. My dental oncologist was adamant about not having my tooth extracted as it is in the path of radiated bone and tissue.
- 3) I met with my dentist who recommended a root canal on that tooth. I took the first available appointment with an endodontist and had a root canal. About \$1,000. (All out of pocket)
- 4) I now have a gap of two missing teeth (lower middle jaw). After several other dental consultations and second opinions I have an appointment with a periodontist who will build and install a permanent bridge. Cost: \$5,000. (All out of pocket).

What could probably have been done in under 2 months is dragging out to 6 months as dental practices are overwhelmed by people like me who put off proper care in a timely manner due to the pandemic. But the root cause impact of all this is dry mouth.

In closing, I had a very healthy oral cavity until cancer and cancer treatment. I didn't have my first cavity until I was in my mid-30s. I grew up in a town that was an early adapter with placing fluoride in the drinking water in the mid-to-late 1950s.

### **Nancy**

I have so many bad symptoms from the radiation therapy I received for tongue cancer and I'm not sure which are caused by xerostomia. I have dry mouth and dry lips much of the time and then sometimes I have saliva dripping from the corners of my mouth. My tongue and gums are sore the majority of the time and the foods I can eat are very limited. If I eat the wrong thing (and sometimes that changes) my tongue will burn and sores may break out. I have been told I may just have to live with it. If I thought there was a product that would help solve all those issues, I'd be eternally grateful. I cannot tolerate mint, as it burns and so many products are mint flavored. I can get by with Biotène® Gentle Mint toothpaste on most days. I have tried XyliMelts and am not sure how much they help. I just bought some Biotène® dry mouth gel and was relieved that it was not mint flavored. It may help for a short time... too soon to tell.

What do I fear as I get older? I am 74 years old. I first had tongue cancer in 2001, breast cancer in 2016, and most recently tongue cancer in 2018. I have the natural fear of some form of cancer returning. I recovered nicely from the first two but the treatments for this second

tongue cancer have really changed my life. So, I would say my biggest fear would be the treatments I'd have to face if something did return. I would be looking for a long-lasting dry mouth remedy that wasn't mint flavored.

**Nan**

After a total thyroidectomy (TT) and two doses of radioactive iodine in 2010, I have lost most of my teeth – I have only the front 13 upper and lower left. I also have lupus/ Sjögren's. Because of the extreme dry mouth dentures aren't an option, and I can't afford implants. If any of my doctors had mentioned this, I never would have had radioactive iodine treatments. And the treatments didn't work. The dry mouth is horrible but not being able to chew is awful. I do NOT recommend this treatment!!!

**Maria**

Xerostomia due to radioactive iodine (RAI) damage of salivary glands and trigeminal neuropathy.

**Jessica**

I need to have top & bottom gums anesthetized even to have a cleaning, as my gums/teeth have become so sensitive since my 225 millicuries (mCi) radiation 3/2003; (2) I dare not snack e.g. in a car, without water nearby to help me swallow, or I'll choke badly; (3) I can't taste red wine anymore! It all tastes metallic! These symptoms developed over a period of years after the radiation 3/2003, starting from 18 months afterwards. (On the other hand, I am still alive and thyroglobulin negligible, which wouldn't have been the case without the radioactive iodine (RAI).) // As I get older (now 70), I worry about losing teeth; I worry about choking. // Management: None of the over the counter (OTC) things make much of a difference. I'm glad my dentist is fine with giving me injections when I have a cleaning, because of the extreme pain when they touch my teeth/gums with anything, and I have cleanings every 3 months rather than 6 months, to nip deterioration in the bud. It would be nice if there were a treatment that decreased the teeth/gum sensitivity, so I didn't need to have my whole top/bottom gums numbed just for a cleaning. It would be nice not to worry about choking, too!

**Michael**

Of all the symptoms of xerostomia, which 1–3 symptoms have the most significant impact on you or your loved one's life? Lack of saliva to swallow, dental decay, difficulty talking.

How does xerostomia affect you on best and on worst days? Describe your best days and your worst days. Worst days, I can't eat the food served to me.

How have you or your loved one's symptoms changed over time? How has the ability to cope with the symptoms changed over time? Getting worse. Anxiety when eating.

Are there specific activities that are important to you that you cannot do at all or as fully as you would like because of xerostomia? Eating many types of foods, no longer participate in aerobic exercise.

What do you fear the most as you get older? What worries you most about your condition?  
Losing my teeth, inability to eat for adequate nutrition.

Your Perspective on Treatment Approaches

What are you currently doing to manage you or your loved one's xerostomia symptoms? Drink lots of water.

How well do these treatments treat the most significant symptoms of xerostomia? Fair

What are the most significant downsides to you or your loved one's current treatments and how do they affect daily life? Limit on types of food, difficulty swallowing, limited social eating, no longer going to restaurants

Short of a complete cure, what specific things would you look for in an ideal treatment for xerostomia? When considering a new treatment, what factors are important to you? Something that can stimulate saliva for a limited time period.

**Susan D.**

I recently had a severe issue with my tongue.

Symptoms were deep fissures, pain, loss of taste. This lasted for 3-4 weeks and was extremely disconcerting. I've never had these issues with such severity before. Cause?? treatment?? my GI doc was horrified when she saw my tongue...would an ENT be a better doctor to see? Help

**Ken**

That's one of the worst side effects. For some reason coke helps. Water doesn't. Gatorade does. None of the medical treatments work. Waste of money. Then I remember what the "year of hell" was like. Minor inconvenience like wearing a mask. You learn to deal with it. I put a Gatorade on my nightstand so when dry mouth wakes me up I sip and good another couple hours.

**Xiaodong**

Significant symptoms (two)

Dry mouth waking up in the morning (minor, doesn't bother at all);

Difficulty swallowing dry food (minor but a nuisance);

The symptoms haven't changed over time. For the swallowing difficulty I need to be constantly mindful of what I am eating as sometimes chewing on a bagel can be uncomfortable and at times scary if a chunk gets stuck at the throat.

This was never life-threatening, but I fear the most as I get older that one day it might become life-threatening. I should always be mindful about the food I eat and have a glass of water nearby.

I don't take any medicine for treatment currently.

**Don**

I am 3-years post treatment for an HPV-related throat cancer for which I received 35 radiation treatments and 3 doses of cisplatin. I am alive and very, very happy. Mostly, I feel great. Related to xerostomia, I would say that I'm at 70% of my pre-cancer levels of saliva. Here's how it affects me. Worst days: if I forget to put a xylitol tablet in my gum before bed, I wake up with a very dry throat. If I am exercising and forget to bring a cough drop or gum, my throat dries out. On one trip, I actually cracked my esophagus and lost three units of blood before I figured out what happened. That was a bad day. So... Xerostomia is my most significant, lingering condition post cancer. I have been offered some free acupuncture treatments and I'll give that a try, but from my reading, I feel like I will live out my life using xylitol tabs and cough drops. Also -- my TEETH. So far, so good. But along with most of my fellow throat cancer patients, I worry about my teeth. So I just keep on brushing and flossing and putting fluoride in little trays to keep dental work at bay. OK. That's my contribution. Ring me up if I can help any more. Thank you for your work! If you have figured out a way to bring me up to 100%, I'd be over-the-moon.

### **Cathie**

I have had xerostomia since July of 2019 after 33 radiation treatments and it has been a living hell. Infections in my mouth, choking constantly and if I don't have water constantly near me, I choke. Because the cancer I have is oral and I've had multiple surgeries I am told they can't do anything to open up my salivary gland. I am sad but I live with it.

I pray for anyone that has this issue and hopefully there will be a solution to help us all.

Thank you

### **John**

I have dry mouth and have to drink water a lot and lock my lips too. My food tastes better if it is moist instead of dry. More mayo, gravy, juicy foods. That helps me swallow easier, too since I have a problem with swallowing.

### **Helene**

First of all, I am thankful for being able to continue my life with a level of quality and confidence. My worst moments are in the middle of the night when my lips feel crusty and my throat is dry. I have learned that my nightstand water bottle is my first friend as I gaze at the clock which usually reads between 2-3am.

My husband is very supportive and is the first one to say "do you need your water bottle refilled?"

After 3 years of one less salivary gland I understand the impact of that loss but I am grateful to spend most of my days enjoying my retirement and spending time with my grandchildren.

I love to sing and have been able to continue doing so, as long as my water bottle is within reach!

### **Louise**

Worst symptoms for me are dry mouth, difficulty swallowing food and burning sensation in the mouth/throat. On my worst days, I believe it affects my sense of taste, or I can barely carry a conversation without coughing and I cannot enjoy some of my favorite foods like chocolate or acidic fruits because of the burning sensation they cause. I also have to drink a lot of

water/liquids to help with swallowing food. Most importantly this has affected my enjoyment of eating.

I'm most worried about increased risk of cavities because of my history and risks if I have to get a tooth extracted. Other concerns are aspirating food and getting pneumonia due to difficulty swallowing. Currently I am managing with some XyliMelts and Biotène® and sodium bicarbonate/salt solution as needed and sometimes using a coconut oil/baking soda toothpaste. These help in their way. Overall, I am mainly concerned with providing moisture and finding ways to prevent cavities. I am dissatisfied with how few choices there are without minty flavorings added to toothpastes or mouth washes. Mint was particularly painful during radiation treatment and not as much now but still an irritant. Are there better options for freshening the mouth without using mint? Important considerations for treatment: cost and side effects.

**Lee**

Dealing with dry mouth is horrible, the Biotène® products don't work for me at all. I deal with it by drinking water 24/7. I'm so dependent upon water bottles, I have panic attacks if I can't take one with me. I love talking and it interferes with that even. I use a humidifier at night, not certain if it helps. I heard from someone who had their saliva gland removed before radiation and put back after. I thought hmmm they must have had good insurance. If I knew this prior, dry mouth, taste, and swollen lymph nodes and swallowing problems I would have reconsidered treatment. And still can't find the primary, a rare case I am! But I keep drinking, eat with gravies, and living normally to most people.

**Dan**

Looking to understand future treatments

**Janet W.**

Dry mouth has seriously cut back my food choices and intake.

Despite pilocarpine, I still lack enough saliva to make my mouth comfortable.

Nothing is worse for sleep than dry mouth at night. I'm up drinking and spraying 2-3 times. Mouth is painful.

**Les**

Dry mouth. Difficulty swallowing food. Cavities developing.

All days the same with the symptoms.

Symptoms have not changed over time.

Have difficulty dining out because it takes so long to eat a meal.

Fear of continued tooth decay and thus, treatments.

Currently, using Biotène® products and constantly drinking water.

Symptoms are manageable with use of products.

No downsides.

Ideal treatment would be a saliva substitute that is effective and easy to use.

**Jesse**



I have had radiation and chemotherapy on my tonsils and throat and my mouth gets severely dry and I can't sleep and have to constantly have water every hour even though I am taking meds for dry mouth. Everywhere I go I must have water with me or my mouth gets really dry like sandpaper.

**Deb**

Happy to be alive and thriving! I drink more water than a parched deer but happy to be able to do that! I warn restaurant servers that I will keep them jumping to refill water. My water jug is my constant companion. AND attitude is my best friend (alongside my husband).

**Angie**

I have this condition from radiation for tongue cancer. It affects my voice, breath and overall feeling in my mouth. It is worse at night. I've tried several products, but some make it worse. With my first tongue cancer 11 years ago, I discovered mango stimulated my saliva. However right now I am not able to swallow safely yet, so I have only tried coconut oil on my tongue, which seems to help.

**Jim**

I don't really have a comment. The symptoms I struggle with most are the lack of saliva while eating and speaking. I need to sip something with almost every bite. The lack of or distorted taste. Some foods are more tolerable than others and some tastes seem to come and go. No food is exciting or something I really want to eat again. I'm eating just to eat/ survive. I also have periods of time when my mouth and tongue are irritated and painful. I had tried one medication for dry mouth near the end of treatment and it caused headaches. At that time, I was not eating solid food, so I stopped taking it. I also tried Acupuncture for dry mouth. I had a little success at that time but it didn't last. I'm looking forward to the webinar just to learn more and possibly find some new options to improve my situation. I am 8 months post treatment.

**David**

I have had xerostomia for nearly 20 years, as a result of a radical neck dissection and radiation treatment of squamous cell cancer of the tonsil in 2001, at age 52. The radiation treatment resulted in xerostomia, almost immediately, and moderate dysphagia, in about 10 years and cardiac issues at about 15 years. These have had the most impact on my life, but which I am still managing and still eat orally. But it takes me twice as long to eat a meal, and maintain oral hygiene. I eat with the help of a small amount of a viscous liquid "smoothy" after almost every mouthful, and cough, to eject any food resting on my vocal cords in my trachea. I eat soft foods with some sort of sauce and floss and brush after every meal, to maintain my teeth - the bottom ones of which have been recently replaced with a full jaw bridge. No extractions or implants are allowed on the lower jaw, because of the risk of osteonecrosis, as a result of lowered blood supply due to the radiation.

Xerostomia occurred during the radiation treatment, and the dysphagia occurred at about 10 years after treatment with the developing fibrosis of the epiglottis (no longer flexible to cover the trachea when swallowing) and esophagus (constricted, requiring smaller amounts to be swallowed).

Because of my eating issues, I avoid eating in restaurants, but do takeout instead. I also have trouble gaining and maintaining my weight, and eat the high calorie smoothies fortified with a weight gain powder, and add avocado oil to my coffee in the mornings.

This has also affected my heart, because of the radiation to the vagus nerve, which controls heart and blood pressure: I have atrial fibrillation (afib) and a labile blood pressure, both now controlled and monitored. Fortunately, my heart was strong to begin with, from an active lifestyle and continuing sports.

Eating this way requires a conscious awareness of how to eat and swallow, which I may not always have. My mother, grandmother and great grandmother all had dementia, and my concern is that if I get dementia, I may choke and/or get aspirational pneumonia.

I have a slight concern that I may require a stomach tube, if the dysphagia gets worse; so far it hasn't. This would also be of concern with dementia; The tube is uncomfortable to have, and is easy to pull out. The tube also is uncomfortable to have while doing many sports.

### **Lillian**

I am a 24 year cancer survivor with very little saliva. I am 51 years old and was diagnosed with nasopharyngeal cancer when I was 27 years old (and pregnant). So many daily challenges. Dry mucous, food issues, interference with speaking, dental, UGH! Very frustrating! Let's just say I keep the water bottle companies in business! I am looking to connect with others dealing with this. I cannot join the seminar but would like to become involved with SPOHNC/Xerostomia groups to see if there are things/tips out there I haven't tried. Thanks!

### **Ross**

Eating and tasting are not as enjoyable as they used to be. I think it has affected my appetite too.

### **Michele**

Suffering with dry mouth since radiation 2009, teeth are all chipped and broken, there is some decay.

### **Ronnie**

I am an eight time Oral, Head and Neck Cancer survivor! I have dry mouth constantly and fight thrush about five out of seven days a week. I'm interested in learning about more ways to help me with these problems!

### **Valerie**

I have suffered from dry mouth since 1999 after treatment for stage III tonsil cancer. It makes everyday living very difficult.

Eating is definitely a challenge. Always need liquids to wash the food down. Tooth damage is a major problem.

I do most things I did before as long as I take the prescription for dry mouth. Symptoms have not changed without medication. I take cevimeline 4x daily. It works okay. I can tell when I need the next pill.

Acupuncture worked well for me, but my insurance would not continue paying past six months, and it needs to be ongoing forever.

I think gene therapy shows promise.

**Yvette M.**

The most worry comes from the fact the condition seems to be getting worse. I used to like to go out to eat - not anymore. I cannot swallow without water - always. Soup and ice cream are my go-to foods all days and every day! I have tried all recommended meds - to no avail. The chemo, surgery and radiation has completely changed my life. I have had one throat dilation, too. Plus, lymphedema massages, masks and suits.

**Donna D.**

I seem to still have every symptom. Some days easier than others.

I had chemo, radiation in fall of 2018. Ended up a year later with left neck dissection. Worsened the dysphasia, speech.

I live alone. Can't eat in front of others with the coughing, clearing my throat and sometimes choking.

I have mastered food prep and variety. It differs from day to day.

Some mornings I can't even speak until I drink water, and use Biotène®.

Interference in simple tasks such as speaking, eating and trying to stay hydrated. Using Magic Mouth Wash to eat and take some meds. Some end up in yogurt. I have been on antibiotics by I D doc for radiation related osteomyelitis in my hyoid bone.

I am self-conscious about speech, drooling, eating, very frustrating for any social engagement.

I miss straws, singing, whistling, my smile. I sound like someone who smoked for years. I never have.

I am a 70-year-old female who swims, lives independently, belongs to a support group, and is a survivor in remission.

I have had to make so many adjustments. Just wish some days that the challenges would not be so overwhelming.

**Hank**

Medical Acupuncture has provided me the best overall relief of xerostomia. After several prescription medications failed to provide relief. I tried a variety of home remedies: special gums, candies, drops, mouthwash with little relief and some causing other issues such as thick sticky saliva. However, the cost of treatment, not covered by insurance, is prohibitive and has caused a financial burden.

An ideal plan would be something that could be self-administered, provide effective relief for many hours and not just a few with minimal side effects.

New treatment should be effective, cost efficient and easy to administer.

**Gary**

Besides constantly hydrating my mouth with water are there any other things I can do to keep my mouth moist?

**Susan C.**

I have comments to all (9) questions that are listed:

Q1) Of all the listed symptoms of xerostomia, which have the most significant impact on your life?

A1) Dry, pasty mouth, difficulty in swallowing most foods, difficulty in sustained talking/singing/exercising

Q2) How does xerostomia affect you on your best and worst day? Describe.

A2) Describing a particularly BAD DAY of xerostomia begins with waking up some mornings with an incredibly dry mouth, tongue and throat: experiencing a sensation of my tongue becoming "carpet-like"; most mornings waking up with a thick mucous-y coating throughout my mouth and back of my throat and my lips are noticeably dry and parched. When doing a morning run (45-60 min), my mouth would dry up within 30 seconds and all mouth moisture would evaporate from the mucosa and my lips. This creates "distress" to my focus and form and convinces me of the need to stop running altogether. While traveling on long distance motorcycle trips, the need to have hydration nearby is very real but it's not always possible to provide that relief, thereby creating another "distressing" mindset and reducing the pleasures of a road trip. Describing a particularly GREAT DAY without the side effects of xerostomia would include all the hydration and cleansing resources nearby and at every meal. My day would pass without me feeling much discomfort/distress (if at all). All of my management strategies are met without interruption.

Q3) Have my symptoms changed over time or the ability to cope with the symptoms changed?

A3) I have become better at identifying ways of managing my xerostomia. Listening and learning what others have done have helped me find what is working FOR ME. Being over 2.5 years post-radiation therapy treatments, I am continually trying to find a better way of making xerostomia a part of my life and the easiest way possible.

Q4) Are there specific activities that are important to me that I cannot do at all or as fully as I would like due to the xerostomia?

A4) The biggest area of my life where xerostomia has limited my usual activity level is physical fitness. I am not able to run or do aerobic/cardio exercises as easily as I once had (pre-radiation treatments). And because my personal physical fitness is extremely important to me, I am determined to find a way of incorporating xerostomia management techniques into my fitness plans.

Q5) What do I fear the most as I get older and what worries me most about my condition?

A5) What I fear the most about my xerostomia is if I were to be rendered unable to talk (ie: coma, life support, ventilator), that my caretakers/nursing staff would not know of my condition, of my discomfort/distress and that no one would provide me with the moisture (whether it be lubricant or liquid) for my parched lips, mouth and throat. Also, because of the persistent sticky, pasty film that constantly develops throughout my mouth and back of my throat when there is no mouth movement (ie: asleep), no one would know of the way that I clean my mouth every morning to make it fresh. No one would know of my saltwater/baking

soda gargle that is of incredible help in keeping my mouth mostly clean and fresh. And I fear that no one would keep my oral hygiene in check to prevent infections and cavities. I think what I fear the most is being present in my mind but physically not able to communicate with those in the "outside world" of my needs.

Q6) What am I currently doing to manage my xerostomia symptoms?

A6) I am currently managing my xerostomia by keeping a high level of oral care/maintenance/cleanliness by brushing my teeth multiple times a day, along with the use of oral sponges to "scrape" the slimy mucus off my tongue and out of the back of my throat, along with utilizing a saltwater/baking soda gargle and flossing. I've been maintaining quarterly dental visits for cleanings and checkups. My dentist has me using a nightly fluoride gel application routine as well as using mouth tapes to tape my lips shut to keep any mouth breathing to a minimum. I have tried Salagen tablets (pilocarpine) and NeutraSal powder (rinse) to help stimulate saliva production with no noticeable improvement. I have since discontinued those products.

Q7) How well have those treatments treated the most significant symptoms of xerostomia?

A7) I believe that my proactive attitude about my oral care is helping me tremendously but I also recognize that this routine is now my new normal and will be lifelong. Artificial treatments (Salagen, NeutraSal) have proven to be not effective FOR ME.

Q8) What are the most significant downsides to my treatments and how does it affect my daily life?

A8) The most significant downside to my oral care treatment that manages my xerostomia is the inconvenience of needing to pack my saltwater/baking soda gargle rinse when travelling, especially for a lengthy trip. I run out of rinse fairly quickly and need to create another batch every few days. This makes packing for a trip a little problematic as I feel anxiety when I can't have access to my rinse to clean out my mouth as needed.

Q9) Short of a complete cure, what specific thing would I look for in the ideal treatment for xerostomia? What factor(s) are important to me?

A9) If there were to be a "cure" for xerostomia, it would be my deepest hope that it does NOT affect the tastebuds. In my particular radiation therapy for throat cancer, my taste receptors were adversely affected (I didn't know it at the time, but it was temporary and fully returned about 1 year post treatment), in addition to my salivary glands being damaged. I experienced a taste aversion to food, water and even my own limited saliva. Malnourishment and dehydration set in, despite my having a feeding tube placed into my stomach. The inability to take in nutrition for months was a dark tunnel in my cancer journey. Post radiation therapy, I was thrilled beyond belief as my tastebuds were returning long after the last radiation therapy session. Unfortunately, my salivary glands have not rebounded (and probably permanently won't) but I have resigned to that fact and I am grateful to have my taste (and subsequent appetite) back. If I were to sacrifice one thing to get rid of the cancer cells within my throat - it ironically would be the salivary glands that stood between the radiation source and the cancer cells. I am beyond blessed that my tastebuds have awakened and the radiation did not kill those

receptors. To this day, I am grateful to eat and taste most normal foods. And I now consider my xerostomia an inconvenience that I am managing and a constant reminder of my battle against the cancer cells that were growing in my body and how I've come through that dark tunnel cancer free.

**Tammy E.**

I just want a doctor to confirm that my dry mouth is from the radioactive iodine treatment, I have been to 3 doctors now that say it's not from that. My saliva glands are always swollen and hard and tender, I drink TONS of water every day, food is always stuck to my teeth. I cannot taste anything sour. And most of all is there anything to do about it to make it better?

**Karen**

I have had radioactive iodine and would like to know what I can do for my mouth pain when I get it.

**Allen**

I imagine that many people living with xerostomia have other issues too. I have biting, chewing, swallowing difficulties (no teeth). I've had partial glossectomy with surgical repair of tongue. I have no sensation from lower lip to neck. It's hard to consider xerostomia independent of my other issues, or even as my biggest problem. I am grateful to learn what I can because anything that may help any of my issues may help me live with the other ones.

**Eugenia**

The symptom that has the most significant impact to me is the sensation of a burning tongue, and feeling the inhaled air as if it's cold passing through my throat causing pain. These result in the feeling similar to inflamed and soreness all over on the back of my face.

My worst day is when my throat feels dry, painful and even exhausting just to have a normal conversation.

What I fear the most is that with age these symptoms can get worse.

**Susan S.**

I am submitting my comments, which may be slightly different from others, but I would appreciate if they were addressed.

1. I have discussed with oral surgeon dry mouth problems, and I feel that I may have a small amount of that, but I have very bad burning mouth issues, which may be related, starting right after RAI. Thyroid was removed due to cancer.

2. It affects eating spicy food, hot food, acid food, etc.

3. All day long it feels like I burned my mouth by drinking hot coffee., tongue, palette, sides. It is very bad, and feels like I can't stand the pain anymore and just want to pull my hair out.

4. Symptoms never have changed. Started 2 weeks after RAI which was about 12 years ago.

5. Only way that it is livable is with medication. My oral surgeon tried lots and lots of different drugs. After about 2 years or longer of this, he tried a combination of 2 drugs which I now use. I now use a combination of Lamotrigine 600mg a day and Clonazepam 3mg, spaced out over the

day. These drugs are being used off label. At the time of that I went to see him (he had already done 2 TMJ surgeries on me, so he wasn't a new doctor to me), he said that mouth pain could also mean heart issues, so I should go see a cardiologist before we start with any drugs. I did that and needed a LAD heart stent. The problem still continued.

6. The pain is tolerable at this time. If I forget to take the medication, I start feeling the pain. The pain is so bad that I don't feel like doing anything.

7. My concern is will I have this forever (probably, according to doctor) and how will the drugs affect me in time.

Hope this info can help someone.

**Ed**

Interest as pertains to Parkinsons?

**Michelle**

Hello! Thank you for this opportunity. I am a speech language pathologist who works with head and neck cancer patients as well as many patients who have dry mouth due to various medications they have to take. So, my questions center around eating and swallowing.

I am wondering if there are any options of artificial saliva or other substances that would help to provide increased saliva production while chewing to help break down food and create a more cohesive bolus for swallowing. I realize this may not effectively target the more encompassing difficulty with xerostomia relief, but am looking for solutions that help people eat and swallow safely and efficiently.

I am also very curious about development of agents or methods that either help the body regenerate effectively functioning salivary glands or, alternatively, would block or prevent radiation's deleterious effect on the salivary glands, cells; anything that could be taken or used during and/or after radiation treatment to improve the integrity of healthy tissue and the ability of the body to continue to function with regard to saliva production.

Last, I have collected questions/comments from my patients, which collectively can be summarized as centering around "true" solutions to saliva production and/or replacement vs temporary symptom relief that has to be repeatedly applied/used.

Thank you so very much for hosting this virtual discussion.

**Mike**

18 years w/ xerostomia post-radiation therapy for throat cancer. Maybe 1 or 2/10 of baseline salivation. \$50K+ of dental care not covered by insurance. Tried prescription meds and acupuncture and neither provided more than temporary relief to 3/10. Rarely sleep through night. Need water bottle or camel back for all activities which rules out or complicates some sports. Key downsides are sleep and dental issues. New treatment should address tooth decay and ability to sleep through night. Ability to eat more normally would be nice.

**Kathie**

All of the stem cell research seems to be aimed at external beam radiation damage only. My damage is from radioactive iodine and I'm not eligible for any clinical trials. Are there less of us? Why are we excluded? Thank you

**Linda**

It affects my swallowing and also my sleep. I can't talk for long stretches.

**Nancy**

I would like to see more products without mint as mint burns my mouth.

**Eric**

I am an HPV throat Cancer survivor, at 45, my life expectancy is far greater than a typical throat cancer survivor. Sadly, now I will live the remainder of my life constantly feeling dry mouth and throat due to radiation. It affects my speech, eating & drinking, and even rest/sleep. I would absolutely make myself available for any tests for a new possible treatment.

**Eleanor**

CPAP use exacerbates the dryness. I would like to know how to manage the effects.

**Lee Ann**

After having a large dose of radioactive iodine for thyroid cancer that affected my salivary glands, I have struggled with dry mouth and difficulty swallowing dry food for the past 10 years. This affects me on a daily basis and affects my career, as I am a trainer and speaker and have trouble getting through a speech. I also have concerns about dental issues due to the dry mouth and the possibility of choking on my food. I manage this condition by constant sips of water and use of XyliMelts when I have to do a lot of speaking. I also am diligent with my oral hygiene and dental check-ups and I avoid dry foods and make sure to take sips of water between bites. It would be wonderful to have a medication or treatment to help with this condition.

**Vlasta**

Thanks!

**Yvette J.**

Is leukoplakia caused by dry mouth?

**Ronnie**

Adding to my previous comments. A big problem I have is choking on my own saliva!

**Anjali**

What led to my xerostomia? The option not offered to select is radioactive iodine. The vast majority, over 80% or more, of thyroid cancer patients have issues with xerostomia due to Radioactive Iodine. Please add that category to your list as these patients deserve to be recognized.

**Sherrill**



What can be done to mitigate extreme dry mouth triggered by Parkinson medication? Drying starts just before taking medication, continues after taking medication, peaks about 1 hour later into total dryness. Tongue and teeth covered with dry paste that must be scraped off, then teeth must be washed using Waterpic, brushed with baking soda tooth paste and prescription fluoride toothpaste.

**Rebecca**

Find that I only can get a few hours of sleep then need to spray my mouth with Biotène®. The thing I miss most is being able to sing in a choir, because my mouth is too dry and so are my vocal cords. I have to eat a lot slower and smaller bites so I don't choke.

**Melinda**

Have dry mouth due to radiation for metastatic thyroid cancer in 2009. It wakes me up several times a night even with use of Biotène® mouth gel. Any suggestions for dealing with this?

**Janet Y.**

The woman from Delaware may want to consider getting a second dental opinion. especially considering her oncologists perspective. Some dentists are not as aware of the consequences of hyposalivation as they 'should' be.

**Rissa**

I had radiation treatments and now I have some saliva back, but my throat seems very dry. Are there saliva glands in the throat? Why is my throat so dry?

**Donna D.**

With eating and taking meds, I spritz with Biotène® to swallow.

I also use magic mouth wash before eating. Lidocaine, Maalox, and Benadryl.

As to sleep, I sleep semi upright at a 45 degree angle.

Had squamous cell in 2018, osteomyelitis from radiation in hyoid bone and left neck dissection after metastasis in March 2020.

**Hank**

I answered Fatigue on the poll to cover: difficulty sleeping, tiring from chewing and swallowing and lack of proper nutrition.

**Dave**

Sleeping has always been an issue, mainly because of the dryness. I was diagnosed with sleep apnea after my treatment, so now use a CPAP. It makes a huge difference in the moisture in my mouth. I still wake up a lot, but the CPAP helps a lot. Maybe xerostomia would qualify people to get a CPAP if it is something that people would like to try.

**Allen**

Most of us suffer from more than one thing. I have had xerostomia for 28 years. Following radiation, I lost all my teeth and some jawbone. In addition to dryness, I cannot easily bite, chew or swallow. 19 years after radiation, I lost half of my tongue. I can speak but am not easy to understand. I can eat anything that is soft wet or mushy. Sleep has been a challenge every night for 28 years.

**Judy**

A number of the panelists mentioned dental health. I too am concerned but find use of Biotène® and fluoride gels hard to tolerate due to the mint they contain. Mint does me in! What are alternatives?

**Ron S.**

Regarding taste as many have mentioned, it appears that spice is a big issue. For me, the tiniest bit of pepper can leave my mouth burning for the rest of the meal. I don't taste sweet at all. Clearing out particles from eating is difficult. I used to like grits. My typical dental care includes flossing, brushing, rinsing with a water pic and then following with an electric toothbrush after every meal and there will still be pieces of food left in my mouth.

**Helga**

I think it's worth pointing out that "dental insurance" is a bit of a misnomer. Most plans have a low maximum benefit amount (i.e. \$1K-2K). It's more of a discount plan rather than insurance. As a result, it's not unheard of for people with xerostomia to rack up massive dental bills.

**Joni**

I find using Salagen 3 times a day and XyliMelts help me greatly. I also rinse many times a day with baking soda and water. I had to train myself to sleep with my mouth closed for the dryness and it helps a lot too.

I find the most difficult things to eat are dry things like bread but the most difficult thing for me to eat is salad! I'm working on ways to be able to go back to eating salads which I love.

**Mike**

The mouth is a sex organ. Xerostomia is a major issue for dating and kissing/oral sex. Bitter irony as the root cause for many of us was HPV STD.

**Scott**

Has anyone mentioned the amount of time it takes to eat? I find at a certain point I'm just done eating because it's already twice or three times as long as a normal person. This results in not getting enough calories. I chew at least 80-100 times per bite.

Also, a caller mentioned replacing teeth with implants using insurance. I am currently going through that process. The insurance has preapproved the implants. (Now I don't know what they will actually pay). I have so far had a pre procedure that pushed bovine and cadaver grains in my sinus cavity where bone needed to regrow in order to secure the implants. Teeth and bone were removed during cancer surgery.

**Janet Y.**

I am curious if anyone has had an experience with preventive dental care - including the use of daily fluoride treatments, use of silver diamine fluoride (a newer preventive approach) or other approaches?

**Janet O'R.**

I exercise regularly for my cardiovascular health and pleasure. But my dry mouth makes running unpleasant - I need to stop every few minutes to take sips of water to wet my mouth.

Horseback riding is impossible - I can't carry water or stop often enough to sip. Has anyone found a work around?

**Lisa**

Not sure I have Xerostomia, but I have severe mucositis. There is a product called Healios that has really helped to calm my mouth irritation. I did have oral cancer, but only required surgery.

**Yvette J.**

My Husband has dry mouth and recently told from a scope July 29th, leukoplakia. Mood swings are more often now. Not sure if it's due to the dry mouth and or anxiety of being diagnosed with squamous cell carcinoma spindle type, but treatments stopped after 7 of the scheduled 28 since March 19. He's now on watch and wait. JULY 29th, the scope and exam show NED (no evidence of disease). Radiation treatments were stopped due to a disagreement of cancer diagnosis between the treating Oncologist and the initial Pathologists report from the VA. It's difficult to cook or buy foods that he likes even after he eats and likes it the 1st eating. We just asked the doctor to prescribe medication for dry mouth because he's tried all the non-prescription options. I don't see callers having mood swings. Overall, we are thankful and blessed. Thank you! God is good and faithful. Our hope is in Him on this journey of watch and wait we are on. Thank you for this conference... from a wife of a person with dry mouth and issues.

**Vidya**

Patients with these oral symptoms, like burning, cracked lips etc. should seek care with an Oral Medicine Specialist. Please look for AAOM (American Academy of Oral Medicine) for help with these issues.

**Angie**

Has anyone tried coconut oil or aloe for dry mouth? Just curious if doctors/dentists recommend any natural solutions?

**Julia**

Are there any strategies one can use while wearing a mask that can help with dry mouth? (i.e. a spray for inside the mask or longer lasting melt or gel for inside the mouth).

**Bob**

My biggest fear is a comment that my oncologist shared on the impact of extensive radiation which is "later problems come later in life." Not knowing what looms ahead is unsettling and actually worse than the xerostomia, trismus or other side effects I currently have.

**David**

I am 20 years out from my surgery and radiation therapy for Squamous cell tonsil cancer, and have had xerostomia since the radiation. I have post-nasal drip which helps to keep my mouth moist, as well as carrying water with me.

But a side effect that I haven't heard yet is cardiac from the radiation affecting the vagus nerve, which runs through the neck area which was irradiated. I developed atrial fibrillation (Afib), and have had both a pulmonary vein ablation, which helped for a few years, and the Maze

procedure, which is helping now. I also have a labile blood pressure (BP), which can vary widely. Both the afib and labile BP my cardiologist attributes to the radiation. I am on Metroprolol and Xarelto for those conditions.

**Kathy**

Drawback of needing to drink water often is that you need to urinate often too. This cycle also leads to getting up frequently at night.

**David**

It's NOT the mint, it's the SODIUM LAURAL SULFATE, or SLS, that burns the mouth. Biotène®, Hello and some Tom's toothpastes have no SLS.

**Julia**

I have found children's flavored toothpaste and mouth washes to be helpful to get away from the mint issues.

**David**

I take 150 mg fluconazole weekly as a prophylaxis against oral candidiasis.

**Charles G.**

I answered as I could for the top 3 to this question: Which aspects of your condition would you rank as most important for a possible new drug or device treatment? What I would like to see in a development is something that comes available soon, without side effects or without it causing another problem. Make it affordable, and easy to obtain. Patients need relief and are suffering.

**Tammy D.**

Ahhhh we got cut off! :( The only other comment I wanted to add is I developed a horrible bad habit as a result of xerostomia...making this sucking of teeth noise. It's a distraction as a public speaker and I've also become very self-conscious about it. I also find myself constantly rolling my tongue over my teeth.

Finally, as a single woman, xerostomia is a huge turn off. Nobody wants to kiss someone with cracked lips, bad breath, sores in their mouth, etc. Those second and third order domino effects are serious! 😞

Thank you for the opportunity to share.

**Ellen**

How do we learn about trials?

**Robert**

In addition to Biotène® Dry Mouth Lozenges I have found Brachs Sugar Free Lemon Drops work very well to stimulate saliva - I buy in bulk of 12 packages of 32 drops each and each lemon drop is packaged separately facilitating being carried in a pocket.

The Xylitol Chewing Gum works well to clean out mucus that accumulates in the morning.

I used to use Biotène® mouthwash but have replaced it with an Amazon private label product which works well, has more moderate taste than Biotène® and is significantly less expensive.

I had Head and Neck cancer treated with simultaneous radiation and chemotherapy.

**Tammy D.**

With biologics and all this stem cell work, is there any research or studies to use platelet-rich plasma (PRP) or stem cell to try and regenerate any of the affected glands?

**AI**

I am 20 months post treatment for throat cancer. I tried pilocarpine with no results. I now take an herbal medicine for 3-4 months with marked improvement in moisture level in my mouth. Rehmannia glutinosa is the chief herb in a traditional recipe, liu wei di huang wan, that has been in use in TCM (traditional Chinese medicine) for millennia. Better research should be conducted on this effective herbal medicine. It appears to offer benefits for xerostomia patients unlike those provided by most, if not all, available Western medical options. Please take this suggestion seriously.

**Ronald**

I noted that no one has had to do what I had to do.

I have had a PEG feeding tube in my stomach for over 2 years and it will be there for life because I can't swallow. I also have a tracheostomy that I keep capped until I start choking on mucus and then I remove the cap so I can breathe while suctioning out the mucus from my throat. The trach is also needed because my vocal cords will not open wide enough to allow me to be intubated. I also remove the tracheostomy cap when I go to bed so I do not choke in my sleep. When my mouth is dry, I can only rinse my mouth and spit out the water because I cannot swallow.

I am used to not eating and seem fine on ISOSOURCE liquid feed.

**Michelle**

This preplanned meeting was very well done and informative. Thank you for all the thoughtful planning and effort that went into this. I am eager to see what comes of it as research moves forward. Huge Thank yous to the panelists, callers and moderators as well as all who contributed to this effort.