



Right Time, Right Place, Right Conversation: Having the Confidence to Talk to Your Family Members About Celiac Disease Screening

*With Kristin Voorhees, M.A., NFCA's Director of Healthcare Initiatives
and*

Christina Gentile, Psy.D., Health Psychology Fellow and member of NFCA's Patient Advisory Council





Important Reminders!

① Will this information be available at a later date?

- Yes, always!
- Webinar recording will be posted along with the webinar slides within **72 hours** after the live webinar ends at CeliacCentral.org/webinars/archive/

② Are continuing education credits available?

- Yes!
- Attendees must **complete the follow-up survey** in order to access this certificate.
 - **The follow-up survey will be sent on Tuesday, May 19th** through an email from NFCA.
- To ensure that you receive this email, make sure that NFCA (National_Foundation_for_Celiac_A@gmail.vresp.com) is on your **allowed senders list**.
 - Accidentally unsubscribed? Register for the webinar with a new email address
 - Be sure your email address is spelled correctly when registering
- Continuing education credits given **for live viewers only**
 - We encourage you to check out our archived webinars, but note that continuing education credit will not be given
- In the case of group viewing, **only the registered and logged in participant will receive credit**





Learning Objectives

- 1) Learn about the research and other work that has gone into NFCA's *Seriously, Celiac Disease* initiative
- 2) Learn by example how to have a conversation about screening for celiac disease with your at-risk relatives
- 3) Explore some of the barriers that may be keeping you from opening an effective conversation
- 4) Discover how you can empower yourself to hold an open dialogue about celiac disease with your family members





Welcome!

Kristin Voorhees, M.A.

- NFCA's Director of Healthcare Initiatives
 - Spearheads NFCA's *Seriously, Celiac Disease* campaign
- Holds a BA in communications from James Madison University
- Holds an MA in health communications from Emerson College/Tufts School of Medicine
- Diagnosed with celiac disease in 2007





Welcome!

Christina Gentile, Psy.D.

- Health Psychology Fellow at California Pacific Medical Center in the San Francisco Bay Area
- Has a special interest in topics such as:
 - GI disorders
 - Health promotion
 - Cognitive-Behavior Therapy
 - Mindfulness-Based Interventions
- Has extensive experience in the fields of oncology, eating disorders, and nutrition and dietetics.
- Diagnosed with celiac disease 12 years ago





Mission to Drive Diagnosis

- NFCA used the National Institutes of Health (NIH) 2004 Consensus Statement on Celiac Disease to guide our organization's strategic plan, part of this included education of physicians
 - NFCA's CeliacCMECentral.com was a free program designed for physicians to support the identification, diagnosis, and management of people with celiac disease
- In 2012, we changed direction based on the needs of the community
- Family member screening is a proactive approach to increasing diagnosis and is recommended by experts
 - "A more proactive case-finding strategy in [family member]s might improve the diagnostic rate of [celiac disease] in North America."¹

¹Rubio-Tapia, A., Van Dyke, C. T., Lahr, B. D., Zinsmeister, A. R., El-Youssef, M., Moore, S. B., ... & Murray, J. A. (2008). Predictors of family risk for celiac disease: a population-based study. *Clinical Gastroenterology and Hepatology*, 6(9), 983-987.





NFCA's *Family Talk* Development

- In 2012, NFCA collaborated with Beth Israel Deaconess Medical Center (BIDMC) and Emerson College to identify the reasons for poor family member screening participation
- Hypothesis: The gluten-free diet is difficult, and that is the reason for poor screening participation
- Research project results:
 - Many untested relatives reported knowing that celiac disease can present without any symptoms, yet the number one reason for not being tested is because they don't have any symptoms
 - 64% of those surveyed said they would get tested for celiac disease if a family member asked them to
 - Need to increase severity and susceptibility
 - Messages about the gluten-free diet are not persuasive

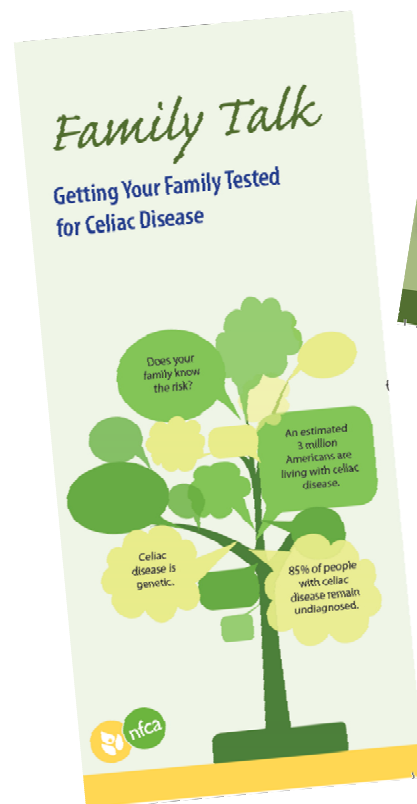




NFCA's *Family Talk*

Created suite of print
and online information:

- Patient and physician brochures/postcards
- Social media activities
- Webinars



Webinars



NFCA's Family Talk

Reach:

- 2013 Celiac Awareness Month: 70,000 +
- January - September 2014: 447,870 +

TALK TO YOUR FAMILY ABOUT CELIAC DISEASE TESTING

Help Keep Your Family Members Healthy. Ask Them To Get Tested For Celiac Disease.

You have been diagnosed with celiac disease. After going gluten-free, you are on the road to restoring health and reclaiming your life.

But, did you know that your family members are at risk for celiac disease? It is critical that all first and second-degree relatives get tested for celiac disease, even if they are not experiencing any symptoms.

Those family members not experiencing symptoms may not understand that they could actually have the disease. They may not recognize their own risk for developing celiac disease, either. What's more, they may not comprehend the potential health risks of undiagnosed celiac disease.

You can make a difference that saves their lives.



CELIAC DISEASE: WHO IS AT RISK?

Both men and women are at risk for celiac disease. People of any age or race can develop this autoimmune condition. However, there are some factors that can increase your risk of developing celiac disease.

1st or 2nd degree relative with celiac disease

Are you diagnosed with celiac disease?

Get tips for talking to your family about celiac disease testing.

Celiac disease is genetically based, so it is more common in those with a family history of the condition. This means that if you have a first or second-degree relative with celiac disease, you are at an increased risk for developing it too. This autoimmune condition occurs in up to 5-10% of family members of persons diagnosed with celiac disease.

Learn more about [Celiac Disease in Families](#).

HLA-DQ2 and DQ8 genes

About 95% of people with celiac disease have the HLA-DQ2 gene and most of the remaining 5% have the HLA-DQ8 gene. Genetic testing can determine if you have one or both of these genes.

It is important to note that having the gene means you are at risk for developing celiac disease, but does not mean that you *definitely* have the disease. A positive genetic test should be followed up with a celiac blood panel to determine if you have celiac disease. If your genetic test returns with a negative result, you can virtually rule out celiac disease.

Some autoimmune diseases

Having an autoimmune disorder makes you more likely to develop other autoimmune diseases, like celiac disease. Other examples of autoimmune conditions can include thyroid disease, Type 1 diabetes mellitus and primary biliary cirrhosis.

[Next: Celiac Disease in Families >>](#)



This resource was created by Claudia Dolphin, MA, as part of the Applied Learning Experience, Master's in Health Communication program at Emerson College. Educational guidance was provided by the National Foundation for Celiac Awareness and the Celiac Center at Beth Israel Deaconess Medical Center. The assistance of Kristin Voorhes, MA, and Daniel Laffer, MD, MS, is gratefully acknowledged. Visit [www.CeliacCentral.org](#) and [www.BIDMC.org/ceeliaccenter](#) and [www.CeliacNow.org](#)



Webinars

www.CeliacCentral.org/webinars
© 2015 All Rights Reserved. 9

CELIAC DISEASE IN FAMILIES

Do you have a family member with celiac disease? Get tested. Here's why.

Celiac disease affects 1 in 133 Americans. The disease occurs in genetically predisposed individuals. That means if someone in your family has been diagnosed with celiac disease, you are at an increased risk for the disease.

1 in 22 first-degree family members (parent, child, sibling) and 1 in 39 second-degree family members (aunt, uncle, niece, nephew, grandparent, grandchild and half-sibling) are at risk for celiac disease. Your risk may double if your brother or sister has celiac disease.

If you are at risk, it is critical that you get tested, even if you have no symptoms. Undiagnosed celiac disease can have long-term consequences, so early diagnosis is key.

[See a list of celiac disease symptoms >](#)

Talking with your doctor about getting tested for celiac disease

Your primary care physician is your partner in health. You both need to be able to communicate openly and honestly. Let your doctor know that you want to get tested for celiac disease. Explain to him or her the reasons why getting tested is important to you.

- You have a family member with celiac disease, which puts you at a risk that is 5 to 10 times higher than the general population.
- Discuss with your primary care provider any concerning symptoms that you have been experiencing. Remember, celiac disease can present in many ways and modern testing is quite accurate.
- Talk about any fears or concerns you have about getting a positive test result. Your primary care provider can help you prepare for any next steps.

Complete NFCA's [Celiac Disease Symptoms Checklist](#) to identify your risk and start this conversation with your doctor.

83% of people living with celiac disease remain undiagnosed or misdiagnosed

Talk to your doctor about testing using these **FREE RESOURCES.**

Next: Celiac Disease Symptoms



This resource was created by Claudia Dolphin, MA, as part of the Applied Learning Experience, Master's in Health Communication program at Emerson College. Educational guidance was provided by the National Foundation for Celiac Awareness and the Celiac Center at Beth Israel Deaconess Medical Center. The assistance of Kristin Voorhes, MA, and Daniel Laffer, MD, MS, is gratefully acknowledged. Visit [www.CeliacCentral.org](#) and [www.BIDMC.org/ceeliaccenter](#) and [www.CeliacNow.org](#)



NFCA's *Family Talk*

- Impact via nationwide survey in November 2014:
 - 90% (N=853) feel somewhat/very confident in ability to start a conversation about celiac disease testing with at-risk, untested relatives
 - 73% (N=853) started a conversation with at least one at-risk, untested relative over past year
 - As a result of family conversations, > 1,679 at-risk relatives have been screened
 - Of the > 1,679 screened, 130 relatives have been diagnosed with celiac disease
- **Despite the engagement and some positive reports, many community members were still receiving pushback and disinterest**





Moving Forward: A Long-Term Strategy

- Identify and understand what messages and strategies will actually stimulate the short-term and long-term results needed to drive diagnosis
- Launched multi-phase project in 2014
- Research results:
 - Confirmation of severity and susceptibility as unconscious barriers
 - Current conversations between family members are ineffective because they lack **direction, purpose, intention**
 - The value of the tTG blood test test versus genetic test
 - Importance of private, one-on-one conversations – this comes back to the **basics of communication**
 - In the digital age, we often forget that there can be value and purpose in face-to-face conversations, because it helps to demonstrate care and that you're taking the topic at hand seriously
 - Diagnosed family members only have **one opportunity** to have this conversation





Transformative Research Results

- We, as diagnosed patients, can also benefit from accepting and better communicating celiac disease's severity
 - Applicable beyond family conversations
- Hypotheses:
 - A long diagnostic process which has involved lack of physician support
 - Self-management of the condition
 - Lack of education and awareness overall in the greater public
 - Balancing the severity of the disease with an available treatment – you can see results so dramatically by going on a gluten-free diet





Evolution into *Seriously, Celiac Disease*

- Employing widely used health behavior change and social science theories to advance celiac disease diagnoses
- Designing the conversation for change within families:
 - Health Belief Model
 - Susceptibility + Severity = Action
- Driving the campaign:
 - Diffusion of Innovations
 - Asking *you* to help drive diagnosis because you are **educated**, you are **motivated**, and you are **able to help** us make as great of an impact as possible

Janz, N., Champion, V. & Strecher, V.. (2002) The Health Belief Model. In *Health Behavior and Health Education Theory, Research, and Practice 3rd Edition* (pp.45-66). San Francisco, CA: Jossey-Bass.

Oldenburg, B. & Parcel, G. (2002) Diffusion of Innovations. In *Health Behavior and Health Education Theory, Research, and Practice 3rd Edition* (pp.312-334). San Francisco, CA: Jossey-Bass.





Seriously, Celiac Disease.

Celiac disease runs in families.

- Research-tested tips and tools to encourage those diagnosed with celiac disease to initiate conversations with their genetically at-risk family members
- Download free resources today:
 - *Dos and Don'ts*, for those diagnosed
 - *Talking to Your Doctor*, for at-risk biological relatives
- Conversations between family members should be held offline and face to face
- Share with others you know living with celiac disease using the hashtag #TalkTellTest

www.SeriouslyCeliac.org



Webinars



Important to Note:

- Your health behavior change, as someone diagnosed with celiac disease, is separate from your untested relatives' but also necessary to spur a lasting impact
 - You must be **comfortable** and **confident** in order to have this conversation
 - Knowing exactly how your family members want to be approached can help build these feelings
 - It's also important to understand why your past attempts may not have worked so that you can move past them





Health Belief Model: Deploying among Diagnosed Patients



Perceived Severity

- Do you think celiac disease is severe/serious?
- Do you think this is a serious conversation worth having?

Perceived Susceptibility

- Do you think you're at risk?
- *n/a in this case*

Benefits Versus Barriers

- Do the benefits outweigh the barriers?
- There are many barriers to having an effective conversation, which we will discuss later

Self-Efficacy

- Do you feel like you are able to have a successful conversation with your untested relatives?
- After having unsuccessful conversations for so long, many patients felt like they were simply unable to have a successful one





How to Have the Conversation

Don't:

- Have the conversation over social media or e-mail
- Use statistics when you talk to them
- Have the conversation at a large family gathering or when food is the focus – in fact, the focus should be away from the gluten-free diet altogether
- Share educational materials with them
- Suggest your relative get the genetic test – don't see value in it
- Talk about testing again unless they specifically ask for a follow-up conversation

Do:

- Have a face-to-face, serious discussion
- Make sure your family member is comfortable, and is interested, engaged, and actively participating
- Relay the facts about celiac disease that are relevant to them – personalize the conversation!
- Highlight the simple blood test that can start the diagnosis process
- Decide on an action plan





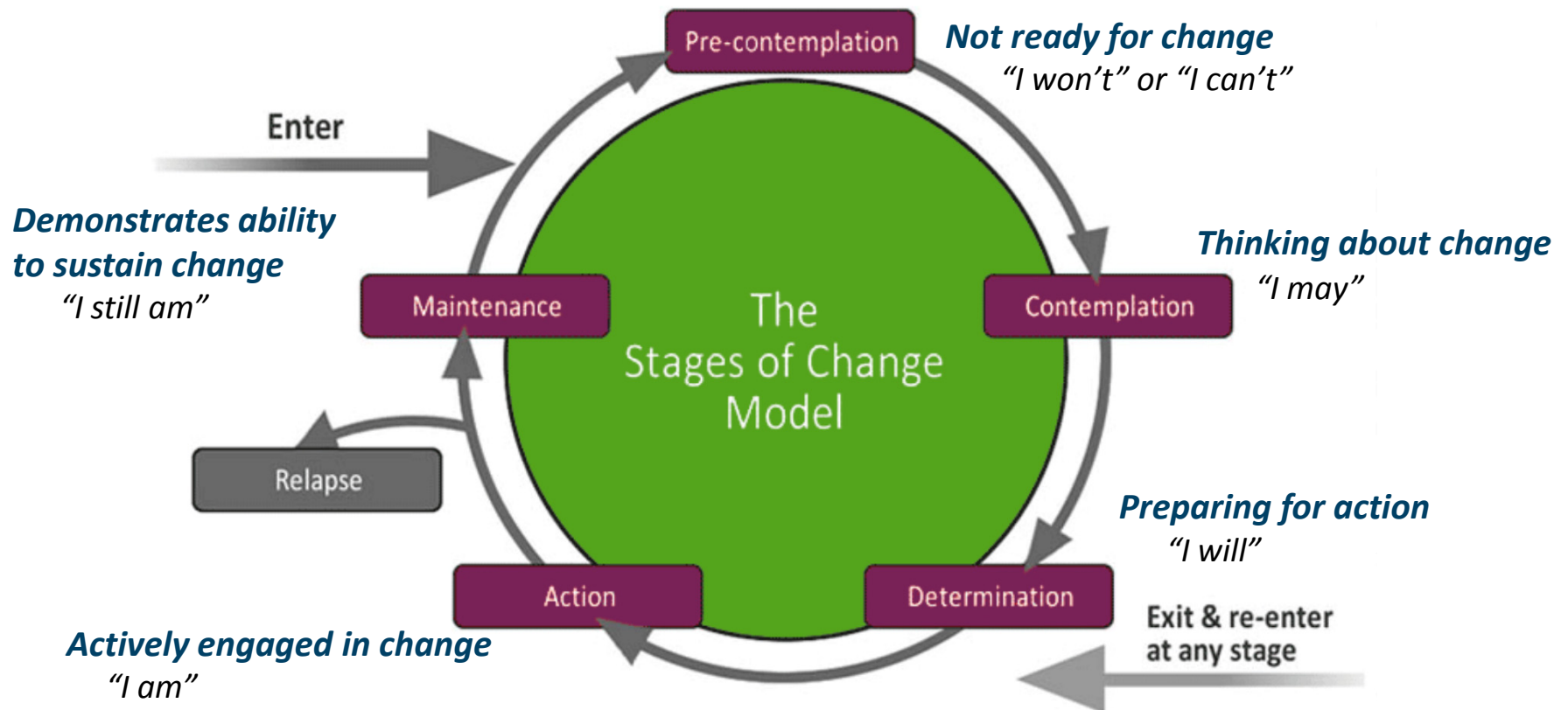
Health Behavior Change is a Process

- People change behaviors because they are:
 - Ready
 - Willing
 - Able
- Change is a process and health behavior change is determined by personal beliefs or personal perceptions:
 - Importance of internal motivators
 - Important consideration when talking about celiac disease and family screening
 - Reminder to personalize the conversation!





Understanding Health Behavior Change: The Transtheoretical Model (TTM)





Using Effective Communication Strategies to Support and Empower Change

3 different communication styles:

Directing

Telling someone what their next step should be and what they should do



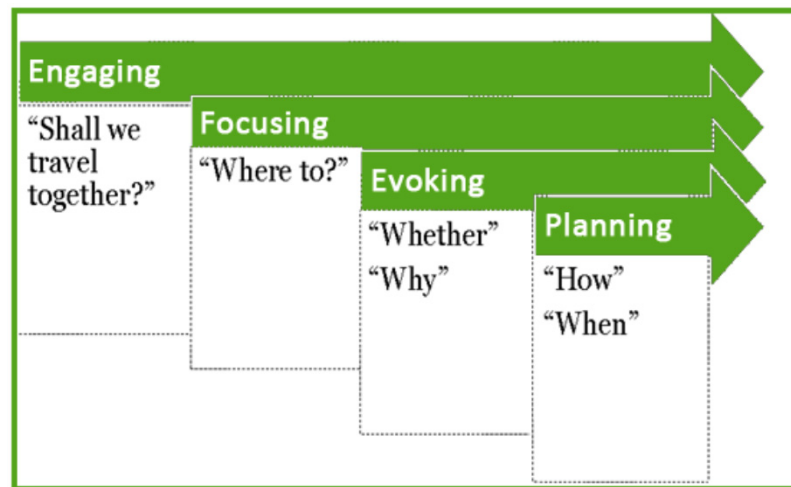
Guiding

Meet in the middle, best tool for behavior change



Following

No agenda, structure, or input; openly listening





Barriers to Effective Communication

Key Barrier: Not Taking Ourselves Seriously

Psychological Factors

- Low self-esteem or self-confidence
- Lack of motivation
- Negative thoughts and emotions

Perceived Outcome Factors

- Afraid of family's reaction
 - Defensive
 - Accusatory
 - Shut-down
 - Reject message
- Anticipating conflict

Stress and Environmental Factors

- Tired
- Availability of resources
- Work demands
- Lack of time
- Busy schedule
- Feeling stuck
- Too much effort





Preparing for Difficult Conversations

- 1. Set your intention**
 - Identify your values
 - 2. Recognize your barriers**
 - Create strategies to overcome any obstacles
 - 3. Develop a plan**
 - Set a date and time
 - Increase your knowledge with additional resources
 - 4. Prepare**
 - Determine potential discussion points
 - Importance and seriousness of celiac disease
 - Pros and cons of celiac disease testing
 - Perceived importance and susceptibility of celiac disease to your family member
- 1. Get your untested biological relatives screened**
 - 2. Internal reflection will help you identify your own personal barriers**
 - 3. Personalize your plan based off of the family member you plan to talk to**
 - Ex: Will they pay better attention when driving or while relaxing on the patio?
 - 4. Download NFCA's Dos and Don'ts Guide to help you prepare for the conversation**





Building Self-Confidence

- **Visualize**
 - Envision positive images of success
- **Practice**
 - Rehearse asking open-ended questions
 - Increase your comfort around the topic
- **Engage in positive self-talk and self-affirmations**
 - Increase your attitude and inner voice with positive self-statements
- **Stress-management**
 - Communicating is easier to navigate when we are calm and more relaxed





Interpersonal Communication Skills:

Opening the Conversation

- **Set the environment**
 - Ensure comfort and privacy
 - Consider the individual needs of your family member
- **Use the common “Ask-Tell-Ask Approach”**
 - Ask permission to start the conversation
 - Provide and share information by following NFCA’s “Talk. Tell. Test.”
 - Ask for understanding , questions, or concerns
- **Examples**
 - “Do you mind if we spend a few minutes talking about celiac disease?”
 - “Can I offer you some important information about other conditions connected to celiac disease that run in our family?”
 - “What other questions about celiac disease do you have?”





Interpersonal Communication Skills: Maintaining the Conversation

- **Provide clear information**
 - Offer information in small, valuable pieces
 - Pause and check-in with your family
- **Ask open-ended questions**
 - Invite dialogue
- **Communicate nonverbally**
 - Nodding, good eye contact, body posture, facial expression
 - Expresses empathy, warmth, and openness
- **Acknowledge emotions**
 - Use simple reflections
 - Accept emotions, do not ignore them!





Interpersonal Communication Skills: Closing the Conversation

- **Conclude with a summary**
 - Discuss main points and ask for any additional questions or concerns
 - Express gratitude and appreciation – reminder to not focus on getting screened for you, it's their health you are concerned about
- **Establish a plan**
 - What is the next step?
 - Let your family member be in-charge of determining the next step, but offer assistance and guidance, if needed
 - Ask your family member if it would be helpful to follow-up with him or her in the near future
 - Connect them to valuable resources to learn more if they're interested
 - [National Foundation for Celiac Awareness](http://www.NationalFoundationforCeliacAwareness.org)





Improve Empowerment and Encourage Motivation

- **Empower your family to make more informed decisions about celiac disease screening**
 - Help explore any ambivalence about the diagnosis process
 - Discuss the benefits and consequences
- **Identify with your family what they might need to increase the likelihood of asking for a celiac disease blood test**
 - What barriers are in *their* way?
- **Emphasize a “team or family approach”**
 - Acknowledge that your family is not alone in the process!





Take Home Points for Managing Difficult Conversations

- **Be present**
 - Cut out all distractions
- **Actively listen**
 - Hold off on judgments or conclusions
 - Open your mind to the unexpected
 - Try to understand where the other person is coming from
- **Be respectful**
 - Speak with care to be accurate, respectful, and connected
 - Be open to and acknowledge emotions that may come up
- **Encourage dialogue and participation**
 - Use open-ended questions
 - Discuss, do not lecture





As we finish...




Questions from the audience?





Thanks to our sponsor – Hain Celestial!



 facebook.com/nfceliacawareness
 @CeliacAwareness
 www.CeliacCentral.org/webinars

NATIONAL FOUNDATION FOR CELIAC AWARENESS
www.CeliacCentral.org



Webinars

www.CeliacCentral.org/webinars
©2015 All rights reserved.30



NFCA Resources

SeriouslyCeliac.org





Stay tuned for more great webinars in 2015!

CeliacCentral.org/webinars





Thank You!

- Webinar questions, comments, feedback: webinars@CeliacCentral.org
- Connect with NFCA:

