Reaching Out To Catholics With Celiac Disease

Mike & Chris Spreitzer
Catholic Celiac Society
Christ powerless over rice, Catholic church says

Church invalidates girl's Communion
The Coast Star
Southern Monmouth County, NJ
By Kara Lott

WAFER ALLERGY BARS PRIESTS
Madeleine Bunting

Customized Communion
Throws A Wedge Into Efforts to Unify
By Bill Broadway Washington Post Staff September 11, 2004

Church denies Communion for girl who can't eat wheat
Church should have mercy on celiac sufferers
BY JULIE DEARDORFF
Chicago Tribune

Bishop won't support mom in communion request
Refuses to ask pope to allow non-wheat hosts
Asbury Park Press 05/18/05

Roman Catholic Church in New Jersey Discriminates Against Sick Girl
Outline

What is Celiac Disease?
- How is it treated?
- Celiac Disease and Holy Communion
  - What is the problem?
  - What can be done?
    - Receive only the Precious Blood
    - Use “low gluten” hosts
    - Spiritual communion
    - Reach out
- The Catholic Celiac Society
Celiac Disease/Celiac Sprue/Non-Tropical Sprue/Gluten Sensitive Enteropathy

An inherited autoimmune disease.

Until very recently, thought to affect roughly 1 in 4,500 in USA.

Now thought to affect roughly 1 in 133 in USA.

→ Over 3 million in the USA.

Most cases still not diagnosed.

Diagnosis rate has increased recently.

NIH consensus statement in 2004.

You will be seeing a lot more diagnosed Celiacs soon!
Celiac Disease

Normal Small Intestinal Biopsy

Changes in Villous Architecture in Untreated Celiac Disease
Celiac Disease:

The inappropriate stimulation of the immune system by cereal grain proteins (gluten) causes damage to lining of the small intestine and other organs.

Malabsorption

Early Onset Osteoporosis

Infertility

Anemia

Peripheral Neuropathy
Celiac Disease:

Inflammatory Response

Secondary Autoimmune Diseases

Diabetes
Rheumatoid Arthritis
Autoimmune Thyroiditis
Sjogren’s Syndrome

Malignancy

Non-Hodgkin’s Lymphoma
Oropharyngeal Carcinoma
Esophageal Carcinoma
Celiac Disease:

Symptoms, sensitivity, and damage in celiac disease present as a spectrum.

There is a great deal of individual variability in “sensitivity” to gluten.

Symptoms, in particular, can not be used as a gauge for gluten exposure or damage.
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Treatment of Celiac Disease

The “Gluten-Free” Diet

Complete removal of offending proteins (found in wheat, rye, barley and possibly oats) from the diet.

Good clinical response to treatment when diet is strictly adhered to.

Increased risk of malignancy seen in untreated celiac disease tends to normalize within five years of strict compliance with diet.
The “Gluten-Free” Diet

When is “Gluten-Free” Really “Gluten-Free”? 

Australian/North American Standard

“No Detectable Gluten” (NDG) Diet is standard treatment recommendation

U.S. food labeling laws currently do not define the term “gluten-free”

European Standard

Includes Codex Alimentarius wheat starch as part of the “Gluten-Free” Diet

Foods may have up to 0.02% gluten and be legally labeled as “Gluten-Free”
The Balkanization of Celiac Disease: The “Gluten-Free” Diet-Myths and Urban Legends

Everybody’s an ‘expert’ because they say so.

No unified national foundation or group.

Many “facts” that are taught to newly diagnosed celiacs have never actually been scientifically proven.

The blessing and the curse of the Internet.

The American Dietetic Association published a standard for the “Gluten Free Diet” in 2000; but this standard is not accepted by all support groups or doctors.
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Holy Communion and Celiac Disease: The Problem

Traditional Altar Bread is not safe for a person with celiac disease to consume.

Recent case report in Italy (Sept 2004) documented continued intestinal damage over two years with daily 1 mg gluten ingestion from Holy Communion (normal wheat host) despite otherwise strict dietary compliance (codex GFD)

Normalized serology

Completely resolved symptoms
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Receive only the Precious Blood

The doctrine of concomitance teaches us that the entirety of Christ is contained in every crumb of bread and every drop of wine. Receiving communion under either species is as good as communion under both.

Consecrated wine is safe for a Catholic celiac to consume provided that it has not come into contact with any wheat.

Gluten is highly soluble in alcohol.
Precious Blood: Logistics

Communion under both species is not available in all parishes, at all masses.

Sometimes it runs out!

The priest’s chalice is not a safe option.

..neither is any other into which the priest has poured some consecrated wine from his chalice.

New norms for distribution of Holy Communion (March 2004) prohibit pouring consecrated wine from one vessel to another.

Celiacs may want to be near the head of the line.

Intinction, while generally prohibited, does sometimes occur.
Precious Blood: Other Issues

Fear of rejection.

People do not want special treatment.

Shyness.

Fear of gluten in the wine.

Based on misinformation (hopefully!)

Alcoholism or sulfite allergy can prevent a celiac from being able to receive mustum or wine.

Anti-drug/alcohol teaching in schools.
How Many Celiacs Feel about *not* Receiving the Body of Christ

- Spiritual Leper
- Marginalized
- Set Apart
- Beggar at the Banquet
- Anxious
- Awkward
- Abandoned
- Isolated
- Devastated
- Singled Out
- Separated
- Unworthy
- Painful
- Difficult
- Second Class Catholic
- Forsaken
Why Do They Feel that Way? Uneven Treatment of the Two Species

Greater respect given the Body in the Liturgy.

The Precious Blood is optional when offered.

Receiving *only* the Precious Blood is specifically prohibited.

The Precious Blood is not always available.

Even greater unevenness before Vatican II.

Uneven emphasis in musical repertory.

Uneven treatment in religious education, special ceremonies, etc.
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Low-Gluten and No-Gluten Hosts

The situation of how Catholic celiacs can safely receive the Eucharist has been reviewed by the Vatican several times.

Cardinal Joseph Ratzinger, Prefect of the Congregation for the Doctrine of the Faith (at that time), sent a letter dated August 22, 1994, providing norms for the use of low-gluten bread (made of wheat flour and wheat starch), and mustum (natural unfermented grape juice).

In 1995, Cardinal Ratzinger specifically addressed the issue of providing Catholic celiacs with a “gluten-free” host.
Low-Gluten and No-Gluten Hosts, cont’d

Cardinal Ratzinger expanded on the canon in the light of the dilemma faced by sufferers of Celiac Sprue disease and made these points:

Special hosts *quiibus glutinum ablatum est* [in which gluten has been removed] are invalid matter for the celebration of the Eucharist;

Low-gluten hosts are valid matter, provided that they contain the amount of gluten sufficient to obtain the confection of bread, that there is no addition of foreign materials, and that the procedure for making such hosts is not such as to alter the nature of the substance of the bread.
Low-Gluten and No-Gluten Hosts, cont’d

The vatican took up the issue again in July 2003. Cardinal Ratzinger reiterated the stipulation that the host be made only of wheat and water and have enough gluten to attain the confection of bread. He also gave permission for celiacs to receive Holy Communion under the species of wine alone.

Authority for the use of mustum was transferred from the Holy See to the local Ordinary (which already had the authority to permit the use of low gluten wafers).

That authority in turn may be delegated to pastors.
In August 2002, the National Italian Conference of Bishops, the Vatican’s Congregation for the Doctrine of the Faith, and the scientific committee of the Italian Celiac Association approved the use of a low gluten host which is made with Codex Alimentarius quality wheat starch and contains 0.0374 milligrams (or 37.4 micrograms) gluten.

In January 2004 the USCCB approved the use of “low gluten” wheat starch based hosts produced by the Benedictine Sisters of Perpetual Hope in Clyde, MO. The upper limit of gluten content in these hosts is 37 micrograms.
The hosts were tested for gluten content by an independent laboratory (American Institute of Baking). The gluten content was reported as “none detected”.

The lower threshold of detection for this test is 0.01%. The hosts are labelled as having this level of gluten as this was the limit of the test that was used.

These hosts could legally be labelled as “gluten-free” here in the U.S. and also in Europe, Canada, and Australia.
Codex Safety: Anecdotal Evidence

The evidence is mixed.

Codex wheat starch based communion wafers have been used by celiacs in Europe for years.

Codex wheat starch based “gluten free” foods and hosts are not always well tolerated by all celiacs.
89 Adults with Long Standing Celiac Disease had duodenal biopsies.

Biopsy results were correlated with Codex GFD (39 patients) vs. NDG (50 patients).

51 patients had normal biopsies, 38 had villous atrophy (partial 28, subtotal 8, total 2).

Form of diet treatment had no significant effect on outcome of biopsies.
Codex “Gluten-Free” Product Acceptance

Unlike Europe, celiacs in North America and Australia have a strong psychological aversion to wheat based products.

Codex “gluten-free” products are generally not purchased by celiacs here and are not carried in health food stores, grocery stores, or by most gluten-free specialty food mail order suppliers.
Living with the Gluten Free Diet

It is impossible to completely eliminate all gluten.

Each celiac must make his or her own trade-offs.

Unless you produce all your own food, you have to rely on information from manufacturers who rarely make strong promises about accuracy or ingredient changes with notice.

You can’t prove a negative: There is no test for any chemical substance that can show truly zero concentration.

Studies of foods thought to be “naturally” gluten-free, like coffee, soft drinks, yogurt, legumes, meats, vegetables, etc. show a surprisingly high presence of gluten (more than 10% of the products had detectable gluten in them).
Arguments Pro and Con the U.S. Approved “Low Gluten” Hosts

Pro: a celiac would have to consume at least 270 hosts per day to reach a level of gluten ingestion that has been shown to be dangerous. (‘‘Gluten Free Living’’ Vol 9 No. 2)

Con: why take an unnecessary risk and ingest anything known to be made of wheat at all?

Con for a parent: it is bad to teach a celiac child to take unnecessary risks.

Con for a parent: mixed message.
Other Issues with “Low Gluten” Hosts

Fear of rejection.
People do not want special treatment.
Shyness.
Uninformed fear of gluten in the hosts.
   Not everyone is as educated as you now are!
Expense.
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Spiritual Communion

The act of praying for the Lord to come to you in the same way as he would if you could physically receive the sacrament.

This option is always available.

Some of the same issues as other options:

- Feeling second class.
- Desire to be included with the rest of the community.
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Reaching Out To Catholics With Celiac Disease

A positive first contact between a celiac and their pastor is critical.

Many Catholic celiacs leave the Church because of a bad initial experience of trying to communicate their special needs to their pastor.

A newly diagnosed Catholic celiac may not have all the knowledge and experience necessary to determine if they can/should receive the “low gluten” host. They need guidance and support.
Reaching Out To Catholics With Celiac Disease

Many Catholic celiacs may need further catechesis in order to understand the Church’s teaching regarding the matter of the Eucharist.

Other parish clergy, religious, and lay ministers, particularly Extraordinary Ministers of Holy Communion need to know about celiac disease and the logistics surrounding helping a Catholic celiac share in the Eucharist.
Catholic celiacs need to feel support from their parish community.

It is increasingly common to find people knowledgeable about this condition within a single parish.

Some parishes have established ministries for Catholic celiacs.

A simple note in the weekly bulletin welcoming Catholic celiacs and inviting them to contact their pastor (or other designated person) helps.
Reaching Out To Catholics With Celiac Disease

Not every Church or social event needs to include food!
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“Ask and it will be given to you; seek and you will find; knock and the door will be opened to you. For everyone who asks, receives; and the one who seeks, finds; and o the one who knocks, the door will be opened.”

Matthew 7:7
The Catholic Celiac Society

Educate Catholic celiacs about their options for Holy Communion as provided for by Canon law and the USCCB.

Inform Catholic clergy and lay ministers about the special needs of Catholic celiacs in their dioceses and parishes

Reconcile those Catholic celiacs who have left the Church through lack of understanding, exclusion from the eucharist, and isolation from their Church community.
The Catholic Celiac Society

http://www.catholicceliacs.org

Started in May 2004.

Several hundred members in over fifty dioceses throughout the U.S., including celiac priests and religious, medical professionals, and laity.

Currently in dialogue with the USCCB about establishing the CCS as an officially recognized Catholic organization.
Backup Slides
Holy Communion and Celiac Disease Issues: Yeast or Grain Alcohol is added to Altar Wine

Altar wine does not have any additives or fortification

The General Instruction of the Roman Missal

Section 322. The wine for the eucharistic celebration must be from the fruit of the grapevine (cf. Lk 22:18) natural, and unadulterated, that is, without admixture of extraneous substances.
A 1998 study by (Ciacci and Mazzacca) of 202 different foods that people with celiac disease considered to be “naturally” gluten-free showed that 21 (10.4%) of these foods had more than 20 ppm gluten. Thirteen (6.4%) had more than 300 ppm.

A 2003 study (Collin et al) showed that 17 of 59 (28.8%) “naturally” gluten free flours had over 10 ppm gluten and five (8.5%) had more than 100 ppm gluten.
The low gluten hosts produced by the Benedictine Sisters are manufactured and packaged in a completely gluten-free environment.