2022
ANNUAL IMPACT REPORT
fight the itch. save a life.
Suspected Intrahepatic Cholestasis of Pregnancy (itching, dark urine, nausea)

Take a history including family history, any history of liver disorders. Laboratory evaluation with CMP and Total Bile Acid tests (Bile acids do not need to be fasting)

- **Bile acids normal (<10 μmol/L) and LFTs normal**
  - Not diagnosable ICP
  - If symptoms continue, repeat CMP and Bile acid testing in 1-2 weeks

- **Bile acids 10-40 μmol/L**
  - **Mild ICP**
  - Stillbirth risk is 0.13%
  - Ursodiol<sup>1</sup>
  - Antepartum testing<sup>2</sup>
  - Delivery 36 0/7-39 0/7 weeks
  - Betamethasone if delivery before 37 0/7 weeks
  - Consider repeat bile acid testing<sup>3</sup>

- **Bile acids 41-99 μmol/L**
  - **Severe ICP**
  - Stillbirth risk is 0.28%
  - Ursodiol<sup>1</sup>
  - Antepartum testing<sup>2</sup>
  - Delivery 35 0/7-39 0/7 weeks with delivery in the EARLY portion of the window
  - Betamethasone if delivery before 37 0/7 weeks
  - Consider repeat bile acid testing<sup>3</sup>

- **Bile acids greater than 100 μmol/L**
  - **Severe ICP with increased risk of complications**
  - Stillbirth risk of 3.44%
  - Ursodiol<sup>1</sup>, consideration of other medications for control
  - Antepartum testing<sup>2</sup>
  - Delivery at the latest at 35 0/7 weeks
  - Consideration for delivery 34-36 weeks with unmitting itching, history of prior stillbirth due to ICP or worsening hepatic function
  - Betamethasone

---

Educational Outreach Program 350

Educational Outreach Program 350
WEBSITE VISITORS

Over 320,000 Views
167,578 Visitors
With over
166,000
of those being first time visitors

EDUCATIONAL BROCHURE DOWNLOADS

Infographic: 1,409
Patient Brochure: 2,213
Healthcare Professionals Brochure: 1,152
Diagnosis & Treatment Flowchart: 788
Considerations After Pregnancy: 26
After two long years, as the pandemic stopped all events, we were excited to represent the cause and the ICP Care Community members again at the in person conference. We were thrilled to have a booth presence at the AASLD The Liver meeting speaking to hepatologists and other specialized physicians and distributing evidence-based educational materials about ICP After Pregnancy. We met and spoke to other rare liver disease organizations attending this conference. Dr. Laura Bonebrake, Medical Advisory Board OBGYN / Board Member and Donna Benavides, CEO / Founder pictured at the ICP Care booth.
**BACKGROUND**

Intrahepatic cholestasis of pregnancy (ICP) is a disorder where bile acid transport is disrupted during pregnancy. Leads to elevated bile acids in the maternal circulation that can affect the fetus. Main risks during pregnancy include preterm labor, respiratory distress of the newborn and stillbirth (up to 3% risk in severe cases). Exact cause is unknown, thought to be a combination of genetic, environmental and hormonal causes. Genes such as ABCB4, ABCB11 and ATP8B1 have been implicated. ABCB4 is responsible for about 15% of cases. Recent research shows there are increased medical risks after an ICP pregnancy and the possibility of an underlying liver disorder being the cause of the elevated bile acids. ICP may "unmask" an underlying liver disorder, sometimes the ICP is the first sign for the patient.

**FUTURE MEDICAL RISKS**

**INCREASED RISK OF HEPATOBILIARY DISEASE INCLUDING:**

- Gallstones
- Pancreatitis
- Non-alcoholic fatty liver disease (NAFLD)
- Cirrhosis
- Increased risk of hypothyroidism and other autoimmune disorders

Studies have shown up to 3.5X increased risk of subsequent hepatobiliary diseases and a significant increase in the need for cholecystectomy. Time to development of future liver abnormalities is also shorter. ABCB4 gene that causes ICP also increases risk for gallstones and may play a common role. Hepatitis C increases risk for ICP and may be responsible for studies which have shown increased risk of cirrhosis and hepatobiliary cancer in patients with ICP.
“Because of this community and the ICP Care website, I was able to advocate for myself and my baby by educating myself and staying up to date on the latest research and recommendations in the scientific obstetric world.”
~Angelina

“If it had not been for the ICP Care website and Facebook groups I would have felt even more lost and alone. I am eternally grateful for the nurse practitioner who raised a red flag, to those who manage the ICP Care website and to the moderators and members of the ICP Care Facebook group.”
~Amelia

“The ICP Care website and support group on Facebook was absolutely wonderful to have. It made me feel less alone knowing that there are other women out there who know and understand exactly how you feel, and know every fear and discomfort you feel.”
~Erika

Crystal’s ICP story video for Pregnancy & Infant Loss Awareness Month

June ICP Awareness Month, Ambassador Ashley's Video
The Wholesome Fertility Podcast, Donna Benavides
A Prenatal Red Flag that Everyone Who is Trying to Conceive Needs to Know by Donna Benavides

The Healthy @Reader’s Digest, Laura Bonebrake
Despite its seriousness, many expectant people have never heard of ICP. This is something Laura Bonebrake, MD – an obstetrician-gynecologist and a mother who experienced ICP in all four of her pregnancies, wants to change.

Health Care Newsletters Publish Patient Stories to Spread Awareness
Board Member Carla Karp's Story: Cholestasis of Pregnancy
ICP CARE
SOCIAL MEDIA

Facebook Support Groups:
OVER 29,500 Members
- 18,000 Public Support Group
- 6,000 Spanish Support Group
- 2,700 After Pregnancy (Postnatal Group)
- 50 State Support Groups

Instagram 4,670
Pinterest 754
Twitter 992
Youtube 476

Video views to date: 51,000
### 2022 Year End Balance Revenue

$14,450.01

### Contributions

- **Grant:** $20,000
- **Fundraiser Events:** $16,341.55
- **Contribution:** $9,211.42
- **Other:** $1,234.19

### Total Income

$46,787.16

### Expenses

<table>
<thead>
<tr>
<th>Expenses</th>
<th>Amount</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness</td>
<td>$30,831.07</td>
<td>60%</td>
</tr>
<tr>
<td>Management</td>
<td>$7,300.00</td>
<td>14%</td>
</tr>
<tr>
<td>Healthcare Conferences</td>
<td>$8,969.10</td>
<td>18%</td>
</tr>
<tr>
<td>Office</td>
<td>$2,211.59</td>
<td>4%</td>
</tr>
<tr>
<td>Fundraising</td>
<td>$914.90</td>
<td>2%</td>
</tr>
</tbody>
</table>
DONNA BENAVIDES: Chair
AMPAKO HEALEY: Vice Chair
LIA MCKERNAN
LAURA BONEBRAKE
KAITLAN TERRY
GRACE ABRAHAM
ELISABETH NAFF
NICOLE LORENTZ
CARLA KARP
SARA-JAYNE CARCERANO

OUR MISSION

ICP Care’s mission is to provide patient support and education, raise public awareness, support the advancement of research and improve health care practices. ICP Care helps to connect, support, educate and empower those affected by ICP – Intrahepatic Cholestasis of Pregnancy.

ICP CARE ANNUAL REPORT 2022 | ICPCARE.ORG