ICP CARE CORP

Miami, FL
http://www.icpcare.org
(320)566-9427

MISSION

ICP Care 501(c)(3) nonprofit charity’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.

We do this by raising awareness of the condition, distributing educational materials for patients and medical professionals, and creating a supportive community for friends and families of anyone affected by ICP. We hope that, one day, all medical professionals and staff will know the proper protocol for treating Intrahepatic Cholestasis of Pregnancy, resulting in less suffering and healthier ICP babies.

EIN
46-5267610

RULING YEAR
2016

IRS SUBSECTION
501(c)(3) Public Charity

FOUNDING YEAR
2008

MAIN ADDRESS
PO Box 12896
Miami, FL
33101

AFFILIATION TYPE
Independent Organization

CONTACT
Donna Benavides-Diaz, Chair - Founder
(954) 401-1714
donna@icpcare.org

CEO - FOUNDER
Donna Benavides-Diaz

BOARD CHAIR
Donna Benavides-Diaz

SUBJECT AREA
Health

NTEE Code
Alliance/Advocacy Organizations (E01)
PROGRAMS

1. Awareness and Educate those affected by ICP – Intrahepatic Cholestasis of Pregnancy.
   Population(s) served: Adults, Women and girls

POPULATIONS SERVED

1. Adults
2. Women and girls

COMPLIANCE

☑ IRS Pub 78 Verified as of July 2024
☑ IRS BMF 509(a) (1) as of July 09, 2024
Section 509(a)(1) organization as referred to in Section 170(b)(1)(A)(vi)

TRANSPARENCY MEASURES

☑ Board Practices Reported?
☑ Diversity Data Reported?
Programs & Results

PROGRAMS

Source: Self-Reported by Organization, April 2024

Awareness and Educate those affected by ICP – Intrahepatic Cholestasis of Pregnancy.

Population(s) Served:
Adults
Females

We raise awareness of the condition via the website, social network media networks, Facebook page and groups, distribute educational materials for patients and medical professionals, and attend 4 yearly Healthcare provider educational events with booth presence. We also create a supportive community for friends and families of anyone affected by ICP.
RESULTS

Number of website pageviews

<table>
<thead>
<tr>
<th>TOTALS BY YEAR</th>
<th>2023</th>
<th>300,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>2022</td>
<td>320,000</td>
<td></td>
</tr>
</tbody>
</table>

Population(s) Served: No target populations selected
Related program: Awareness and Educate those affected by ICP – Intrahepatic Cholestasis of Pregnancy.
Notes: Over 320,000 views
167,578 Visitors
With over 166,000 of those being first time visitors

Number of downloads of the organization's materials and explanations

| TOTALS BY YEAR | 2022 | 5,588 |

Population(s) Served: No target populations selected
Related program:
Notes: Infographic: 1,409
Patient Brochure: 2,213
Healthcare Professionals Brochure: 1,152
Diagnosis & Treatment Flowchart: 788
Considerations After Pregnancy: 26

Hours of volunteer service

<table>
<thead>
<tr>
<th>TOTALS BY YEAR</th>
<th>2023</th>
<th>3,500</th>
</tr>
</thead>
<tbody>
<tr>
<td>2022</td>
<td>4,000</td>
<td></td>
</tr>
</tbody>
</table>

Population(s) Served: No target populations selected
Related program:

Number of patients in ICP Patient Registry to advance and support Cholestasis of Pregnancy treatment, management, and research: launching in 2023

| TOTALS BY YEAR | 2023 | 400 |

Population(s) Served: No target populations selected
Related program:
Notes: ICP Patient Registry is launching in 2023. Our goal is to have 100 patients registered in 2023.

Members in Facebook Support Groups

<table>
<thead>
<tr>
<th>TOTALS BY YEAR</th>
<th>2023</th>
<th>29,600</th>
</tr>
</thead>
<tbody>
<tr>
<td>2022</td>
<td>29,500</td>
<td></td>
</tr>
</tbody>
</table>

Population(s) Served: No target populations selected
Related program:
Notes: Over 29,500 members
18,000 Public Support Group
6,000 Spanish Support Group
2,700 After Pregnancy (Postnatal Group)
50 State Support Groups
CHARTING IMPACT

What is the organization aiming to accomplish?

We 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.

- Continuing Medical Education Programs development on ICP for Healthcare Providers
- Maintain the ICP Patient Registry to advance and support cholestasis of pregnancy treatment, management, and research
- Attend Healthcare professional’s education events with booth presence
- Raise awareness via Social Media Networks and Website Visitors
- Provide support Community Group Members
- Distribute education materials
- Support research

What are the organization's key strategies for making this happen?

ICP Care distributes educational brochures and pamphlets to both patients and medical providers regarding Intrahepatic Cholestasis of Pregnancy. These educational materials provide the information needed to help an expectant mother or health care provider recognize the symptoms of ICP, test for the disorder, and ultimately treat and manage an ICP pregnancy. This information is presented in a succinct and easy-to-digest format and is available to the public at no cost on our website, www.icpcare.org

We manage the world's most visited charitable website on the condition. This website provides evidence-based information regarding ICP, with sections for both patients and providers, as well as links to all relevant supporting journal articles. Also included are links to healthy eating suggestions for pregnancy, “find a doctor” section, doctor discussion guides, educational brochures and many other self-help tools. The website receives over 5,000 unique views each week. Maintaining a visible and highly active social media presence, ICP Care promotes education and awareness of the condition through social media posts on Facebook, Twitter, Pinterest, Instagram and YouTube.

ICP Care promotes education through various media outlets, providing interviews for television, newspaper, and magazine articles. Many of our featured stories such as CNN iReport, What to Expect, Washington Post and Midwifery Today can be viewed by visiting our website: https://icpcare.org/about/news/

Each June, ICP Awareness month, ICP Care organizes and carries out awareness strategies through social media and other campaigns to bring discussion of the condition into public view. These campaigns may include, but are not limited to, educational material, banners, awareness videos, photographs, or other “shareable” social media posts, or any other social media campaign. We also provide documents for individual members to personalize to thank their doctors for their care or to contact local media outlets to raise additional awareness of the condition.

Healthcare Professional Conference / Meetings
In 2018 we attended 3 major healthcare provider conference meetings in the USA to distribute ICP Healthcare provider brochures and educate doctors, midwives and nurses. In 2019 we added the SMFM (Society of Maternal Fetal Medicine specialist) Annual Scientific Conference. In 2020 due to Covid attended SMFM. Returned in 2022 to attend AASLD The Liver meeting and in 2023 have attended SMFM's annual pregnancy meeting.

ICP Care sponsors and manages active and vibrant support groups for women and families impacted by ICP. These support groups are centered around Facebook social media. Support groups include a public group, a closed private group, a Spanish language and Postnatal forum, an In-Memory for support of families of pregnancy loss due to ICP, as well as many local group forums to connect and empower families affected by ICP, including, groups for Canada, Australia, and by state.

What are the organization's capabilities for doing this?

- Continuing Medical Education Programs development on ICP for Healthcare Providers
- Maintain the ICP Patient Registry to advance and support cholestasis of pregnancy treatment, management, and research
- Attend Healthcare professional’s education events with booth presence
- Raise awareness via Social Media Networks and Website Visitors
- Provide support Community Group Members
- Distribute education materials
- Support research
ICP Care manages the world's most visited charitable website on the condition.

**What have and haven't they accomplished so far?**

ICP Care goals accomplished and continued goals:
- Collaborated to add ICP to Michigan State University's Maternal 911 Modules for Maternal Safety Program
- Launched and maintain the ICP Patient Registry to advance and support cholestasis of pregnancy treatment, management, and research
- Continued Goal for future Continuing Medical Education Programs development on ICP for Healthcare Professionals
- Attended (3) 2018 & (4) 2019 & (1) 2020 & (1) 2022 – Healthcare provider education events with booth presence, attended 1 so far in 2023
- Raise awareness: Over 320,000 website views in 2022
- Continue to grow our social media networks; in 2022, over 29,500 members in Facebook support groups, Instagram: 4670 followers, Twitter: 992 followers. YouTube has had over 51,000 views to date.
- Provide support 29,500 Community Group Members
- Distribute education materials for patients
- Goal to print and distribute in healthcare offices for patients
- Support research
## Financials

Source: Self-Reported by Organization, April 2024

**FISCAL YEAR START:** Jan/01  
**FISCAL YEAR END:** Dec/31

### Revenue & Expenses

<table>
<thead>
<tr>
<th>Revenue</th>
<th>2022</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions, gifts, and grants</td>
<td>$29,211</td>
</tr>
<tr>
<td>Program service revenue including government fees and contracts</td>
<td>$0</td>
</tr>
<tr>
<td>Membership Dues</td>
<td>$0</td>
</tr>
<tr>
<td>Net Income from Special Events</td>
<td>$16,342</td>
</tr>
<tr>
<td>Amazon Smile, Cafe Press store</td>
<td>$1,234</td>
</tr>
<tr>
<td><strong>Total Revenue</strong></td>
<td><strong>$46,787</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expenses</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Program</td>
<td>$39,800</td>
</tr>
<tr>
<td>Administration</td>
<td>$7,300</td>
</tr>
<tr>
<td>Fundraising</td>
<td>$915</td>
</tr>
<tr>
<td>Payments to Affiliates</td>
<td>$0</td>
</tr>
<tr>
<td>Website hosting, website maintenance upgrade such as the spanish version, awareness materials such as banners and printing of patient brochures</td>
<td>$2,212</td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td><strong>$50,226</strong></td>
</tr>
</tbody>
</table>

### ASSETS AND LIABILITIES

| Total Assets                                                           | $0    |
| Total Liabilities                                                     | $0    |
| Net Assets or Fund Balance at the end of year                         | $14,450|