IC/BPS Symptom Burden
Results from an Interstitial Cystitis Association (ICA) Survey

Supported by an unrestricted grant from Aquinox Pharmaceuticals, Inc.
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Survey Response

• Interstitial Cystitis Association (ICA) constituents were asked to share their experiences of living with IC/BPS with the ICA to bring the patients voice to the FDA

• Response rate: 2.5% (1133/45,000)

• Survey open for comment for 7 days
  – 130 responses in 30 minutes
  – 230 responses in 1 hour
  – 892 responses in 24 hours
# Survey Demographics

<table>
<thead>
<tr>
<th>Parameter</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Time since onset of symptoms, years</td>
<td>17 years</td>
</tr>
<tr>
<td>Time since diagnosis, years</td>
<td>12 years</td>
</tr>
<tr>
<td>Sex, % (n)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>93% (1038)</td>
</tr>
<tr>
<td>Male</td>
<td>7% (79)</td>
</tr>
<tr>
<td>Race, % (n)</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>93% (1049)</td>
</tr>
<tr>
<td>Black</td>
<td>1.7% (19)</td>
</tr>
<tr>
<td>Asian</td>
<td>&lt;1% (7)</td>
</tr>
<tr>
<td>Other</td>
<td>2.6% (29)</td>
</tr>
</tbody>
</table>

5 year difference

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Bladder Pain is the Most Bothersome Symptom

N=602 selected one symptom as being the most bothersome; Participants were asked to “rank the following you may experience with your IC/BPS based on how bothersome they are to you.” If the participant selected other, they were asked to specify the symptom.

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IC/BPS Symptoms are Terribly Bothersome: Bladder Pain

N=1124; Participants were asked to “select the one number that best represents how much that symptom bothers you on average each day over the last week. Choosing the number 0 represents that symptom doesn’t bother you at all and 10 being it is terribly bothersome to you and interferes with your daily life, activities and relationships.”

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IC/BPS Symptoms are Terribly Bothersome: Bladder Pain and Urinary Symptoms

N=1124; Participants were asked to “select the one number that best represents how much that symptom bothers you on average each day over the last week. Choosing the number 0 represents that symptom doesn’t bother you at all and 10 being it is terribly bothersome to you and interferes with your daily life, activities and relationships.”

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Patients with IC/BPS Describe Their Bladder Pain as Horrible

N=1114; Participants were asked to use one word to describe their bladder pain.

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Patients with IC/BPS Qualify Their Bladder Pain as a Burning Sensation

N=1114; Participants were asked to use one word to describe their bladder pain.

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Patients with IC/BPS Identify Their Bladder Pain as Debilitating

N=1114; Participants were asked to use one word to describe their bladder pain.

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IC/BPS Negatively Impacts Quality of Life

IC/BPS negatively impacts:

- Sexual intimacy: 87.6%
- Personal relationships: 81.4%
- Physical activity: 80.9%
- Travel: 80.4%
- Career: [VALUE].0%
- Social life: 54.2%

N=1127; Participants were asked to select true or false to statements about the effect IC/BPS has physical activity, social life, travel, career, sexual intimacy, and personal relationships.

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IC/BPS Negatively Impacts Quality of Life

IC/BPS has caused:

- Feelings of anxiety: 81.8%
- Feelings of depression: 70.6%
- Feelings of isolation: 65.6%
- Consideration of suicide: 24.6%

N=1127; Participants were asked to select true or false to statements about the effect IC/BPS has on feelings of anxiety, depression, and isolation, and whether they have considered suicide.

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Patients with IC/BPS Want Medications to Treat Bladder Pain

If a medication treated my bladder pain but not my urinary symptoms, I would want to try it

If a medication were available that treats some of my symptoms but not all of them, I would want to try it

N=1127; Participants were asked to which extent they agree or disagree with the above statements.

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Patients with IC/BPS Want a Medication That Addresses Bladder Pain

N=1117; Participants were asked “If you could change one thing about your condition with a medication, what would it be?”

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