Voices of the Community: Commentary
“There has been a shift in healthcare culture from a top-down, provider-centric system to a system focused on patient-centered health outcomes. Involving the patient in the healthcare and decision-making process is a relatively new concept. There is a growing recognition that involving the patient, or consumer, in decisions around their care enhances the quality of care received and improves health outcomes. Consumer involvement at all levels of the healthcare process is critical to the development and delivery of best practices.”

A statement by the Consumer Advisory Group of the National Genetics Education and Consumer Network (2014)
To create an effective healthcare system for individuals and families with genetic conditions, we must first listen to their voices and their needs.”
“Take Aways” from National Survey

• Majority receive care from **multiple providers**
  • Only 1 in 5 people had someone that helped **arrange/coordinate their care**
  • 31.% Very/Dissatisfied w/ **communication among doctors/other providers**

• 42% never or rarely received **social/emotional support** from healthcare provider/support group

• 33% **referred to support** by their healthcare provider

n=1895
## Identification

### Time to Diagnosis By Age Group

<table>
<thead>
<tr>
<th></th>
<th>Children (0-17 years)</th>
<th>Adults (18+)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1 month</td>
<td>15.3%</td>
<td>7.9%</td>
</tr>
<tr>
<td>1-6 months</td>
<td>15.8%</td>
<td>8.2%</td>
</tr>
<tr>
<td>6 months-1 year</td>
<td>15.8%</td>
<td>8.4%</td>
</tr>
<tr>
<td>1-2 years</td>
<td>13.1%</td>
<td>6.6%</td>
</tr>
<tr>
<td>2-5 years</td>
<td>14.4%</td>
<td>8.4%</td>
</tr>
<tr>
<td>5+ years</td>
<td>13.1%</td>
<td>47.2%</td>
</tr>
<tr>
<td>Diagnosed before symptoms</td>
<td>12.4%</td>
<td>13.2%</td>
</tr>
<tr>
<td>Average age at diagnosis</td>
<td>2.7 years (SD=3.8)</td>
<td>29.0 years (SD=19.9)</td>
</tr>
</tbody>
</table>
Access to Care and Support

Biggest Barrier Experienced Accessing Services (n=933)

- Lack of providers with expertise in specific condition: 26.5%
- Cost/Providers do not accept your insurance: 20.5%
- Availability or wait time for appointment: 13.5%
- Distance: 9.8%
- Lack of referral: 6.9%
- Don’t know what you need: 5.8%
- Length of time it take for insurance approval: 5.5%
- Don’t know: 3.6%
- Other: 8.0%

21.7% of respondents did not experience any barriers
Improving Access to Care

From whom they would be most comfortable receiving information (n=933)

- Fellow parent/individual with a condition: 35.9%
- Care coordinator within specialist’s office: 28.9%
- Support/advocacy organization: 14.8%
- Care coordinator within primary care doctor’s office: 9.8%
- Telephone helpline: 3.4%
- Care coordinator at insurance company: 2.8%
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Natasha F. Bonhomme
Chief Strategy Officer
nbonhomme@geneticalliance.org