Life Sciences – The Role of Patient Advocacy

In partnership with BioNJ and MassBio®, Merrill Corporation recently surveyed professionals in patient advocacy roles at life sciences companies. This infographic illustrates how companies view the patient advocacy function in support of their business objectives.

COMPANIES CONTINUE TO ESTABLISH PATIENT ADVOCACY ROLES IN-HOUSE

How long has advocacy been a function at your company?

<table>
<thead>
<tr>
<th>Duration</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>&lt; 1 year</td>
<td>16%</td>
</tr>
<tr>
<td>1-2 years</td>
<td>35%</td>
</tr>
<tr>
<td>3-4 years</td>
<td>16%</td>
</tr>
<tr>
<td>5-10 years</td>
<td>19%</td>
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<tr>
<td>11+ years</td>
<td>14%</td>
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FOCUS AREAS OF COMPANIES’ PATIENT ADVOCACY ROLES AND SERVICES IS VERY BROAD

What platform does your company research?

- Small molecule: 39%
- Biologics: 24%
- Gene therapy: 19%
- Gene editing: 10%
- Other: 8%

Total number of staff devoted to patient advocacy?

- One to Three: 49%
- Zero: 16%
- Seven to Ten: 14%
- More than Ten: 7%
- Four to Six: 4%

What’s the annual patient advocacy budget?

- More than $200K: 50%
- $0 - $50K: 21%
- $51K - $100K: 17%
- $101K - $200K: 12%
What is the primary type(s) of patient advocacy your company is currently practicing?

- 35% We work with patient advocacy organizations as partners and advisors (i.e.: research and development, coalitions and policy work).
- 28% We provide funding for patient advocacy activities and support fundraising efforts.
- 20% We have employees that are volunteers in the disease community.
- 8% We have a consultant or PR firm handling advocacy outreach.
- 5% Other
- 4% None of the above. My company is not involved in patient advocacy.

Do patient community leaders or individual patients visit your company for educational purposes?

- 70% Yes
- 30% No

What activities does the advocacy function touch?

- General support of patient advocacy groups: 26%
- Awareness activities: 25%
- Trial recruitment: 13%
- Protocol development: 12%
- Post-study activities: 10%
- Indication selection: 8%
- Other: 6%
In what ways does your advocacy group work with patient organizations?

- Unbranded awareness for disease education: 24%
- Grants support: 23%
- Research projects: 17%
- Unrestricted operating support: 15%
- Brand awareness specific to trial: 14%
- Other: 7%

How does your organization define success in your advocacy function?

- Incorporating the patient voice in all areas: 28%
- Increased patient access: 22%
- Providing education and resources: 22%
- Support raising awareness and advocates: 12%
- Increasing recruitment: 10%
- Increasing partnerships: 6%

BioNJ is a trade association of nearly 400 Member companies representing research-based life sciences organizations and stakeholders dedicated to propelling a vibrant ecosystem where Science is Supported, Companies are Created, Drugs are Developed and Patients are Paramount. Because Patients Can’t Wait®, BioNJ supports its Members in the discovery, development and commercialization of therapies and cures that save and improve lives and lessen the burden of illness and disease to society by driving capital formation, fostering entrepreneurship, advocating for public policies that advance medical innovation, providing access to talent and education and offering a cost-saving array of critical commercial resources. For more information about BioNJ, please visit www.BioNJ.org.

MassBio® is a not-for-profit organization founded in 1985 that represents and provides services and support for the world’s leading life sciences supercluster.

MassBio is committed to advancing Massachusetts’ leadership in the life sciences to grow the industry, add value to the healthcare system and improve patient lives.

Representing 1,000+ biotechnology companies, academic institutions, disease foundations and other organizations involved in life sciences and healthcare, MassBio leverages its unparalleled network of innovative companies and industry thought leaders to advance policy and promote education, while providing member programs, events, industry information, and services.