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**Proponent Testimony in Support of HB 412  
Health, Human Services, and Medicaid Committee | Ohio Senate | June 3, 2020  
Howie Beigelman, Executive Director, Ohio Jewish Communities**

Chairman Burke, Vice Chair Huffman, Ranking Member Antonio, and Members of the Committee:

As the statewide government advocacy, public affairs, and community relations voice of Ohio's eight Jewish federations, Ohio Jewish Communities submits this testimony today in support of HB 412, to establish the Ohio Rare Disease Council.

**Statement of Interest**

We make this statement of support today on behalf of our communities statewide as well as in support of other communities and individuals with rare and/or genetic diseases.

Within the Jewish community, research indicates a higher than average "carrier rate" on approximately forty different diseases. As of today, each of those diseases is incurable. Some are fatal.

Others, however, are able to be effectively managed with appropriate therapies and protocols.

**Council Can Make Progress**

What is needed here in Ohio is a place for all stakeholders to meet, and to discuss emerging needs.

The proposed council would help coordinate responses to the needs of patients and caregivers. It can help ensure new drugs are available and are affordable.

**Opportunity for Ohio Too**

This would be a win for Ohio too. Already a leader in life sciences and healthcare, the council could help Ohio become a leader in innovation and in next generation pharmaceuticals.

As one example, a new drug therapy shows promise to improve the lives of those affected by cystic fibrosis.

**Current Events Make This All the More Imperative**

We are witnessing today how complex, and even deadly, underlying conditions can be. Those states most hard hit by the COVID-19 pandemic offer compelling statistics. Underlying conditions account for a significant number of the most serious cases and deaths from the virus<sup>1</sup>.

Ensuring those with underlying – and in this case rare, diseases requiring significant expertise for effective treatment – get the care they deserve is always important. During a public health crisis, it is even more necessary.

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<sup>1</sup> See e.g. these reports: <https://www.dispatch.com/news/20200519/60-of-ohio-coronavirus-deaths-have-occurred-in-long-term-care-facilities>, <https://www.kpbs.org/news/2020/may/30/more-half-san-diegans-who-died-covid-19-had-high-b/>, <https://whdh.com/news/nearly-every-mass-coronavirus-death-was-patient-with-underlying-medical-condition-data-shows/>, <https://www.fox9.com/news/underlying-health-conditions-linked-to-98-8-of-covid-19-deaths-in-minnesota>

### **Conclusion and Next Steps**

Enacting this legislation and providing the council with the opportunity to craft a way forward for all stakeholders will help patients, their families, providers, insurers, and regulators will offer real benefits to each group alone, as well as all of Ohio. We urge the General Assembly's support.

Please reach out for any additional information. Thank you.

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Howie Beigelman, Executive Director

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