

January 2018

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Wilson Disease Centers of Excellence Policy

The WDA is a national 501(c)(3) organization, with a global presence in over fifty other countries, serving as an advocate and resource for individuals and families dealing with Wilson's disease. It disseminates scientific, clinical and adaptive information to its members and the treating community through direct communications, printed materials and its excellent web site (<http://www.wilsonsdisease.org>). It has an active membership, regular board and membership meetings, and adequate finances to meet its organizational objectives.

Designation as a Wilson Disease Center of Excellence would likely result in the referral of approximately five new pediatric/adult patients annually. They would be patients with acute and chronic illnesses. Wilson disease patients will require care from hepatologists, neurologists, psychiatrists, dieticians, physical and rehabilitation therapists, social workers, speech therapists and an hepatic transplantation program. Since the United States' Wilson disease population reflects the general population, a significant number will be adequately insured.

As a Wilson Disease Center of Excellence, a medical institution would have:

- access to patients with a fascinating and challenging genetic disease who will benefit from, and live normal lives with, first quality medical care
- an opportunity for research in copper metabolism and its genetic links
- benefit of the WDA's efforts to support educational outreach to healthcare professionals

While Wilson disease has become a subject of media attention, it is not likely that designation as a Center of Excellence will significantly enhance the institution's reputation. However, it will augment its educational mission.

In designating an academic medical center as a Center of Excellence, the WDA seeks to identify a medical center which will render the highest quality care to acutely presenting and chronically ill Wilson disease patients involving hepatology, neurology, nutritional consultation, psychiatry, ENT, physical and rehabilitative medicine and speech therapy. As a Center of Excellence, an institution must provide a site where:

- One or more health care professionals will enthusiastically commit to the care of Wilson disease patients and will coordinate every facet of their care.
- Physicians are well trained in the diagnosis and treatment of patients with Wilson disease.
- Education of the next generation of physicians to care for these patients will occur.
- Clinical diagnostic laboratory studies for metal analysis and related testing are performed.
- Basic research into the underlying pathophysiology of disorders of copper metabolism is conducted, and new experimental therapies for this disorder can be evaluated.
- Patient, family, public and continuing medical education are promoted.

In addition, the medical center, through its designated faculty, must be willing to act as an educational and consultative resource to patients, physicians, and other health care professionals concerning the diagnosis, treatment, and management of Wilson disease. It is also of great importance that communications between the institution and the Wilson Disease Association be easily facilitated as appropriate. The Center of Excellence will be willing to participate in and support WDA initiatives (e.g. Tissue Banking, New Born Screening)

In order to be considered for designation, the interested party should submit a proposal to the WDA President outlining the institution's plan to meet the above criteria. Names, qualifications, and prior experience with treating Wilson disease of each team member should be included. The actual selection of the Center of Excellence will be done by the WDA Board of Directors, with the advice of its Professional Affairs Committee and input from the Medical Advisory Committee.

In order to remain a Center of Excellence, WDA will recertify at least once every three years by questionnaire and will keep the Website updated. Completion of the questionnaire is required and failure to comply may result in revocation of the Center of Excellence status.