

Development of the Accredited Duchenne Centers Program, a Global Program to Achieve Uniform and Up-to-date Care for All People Living with Duchenne Muscular Dystrophy

Imelda JM De Groot¹, Karolina Podolská¹, Nathalie Goemans², Elizabeth Vroom¹

¹World Duchenne Organization, Veenendaal, The Netherlands

²Chair Advisory board Accredited Duchenne Centers Program, Leuven, Belgium

Article Info

Article Notes

Received: August 27, 2025

Accepted: September 12, 2025

*Correspondence:

*Dr. Imelda JM De Groot. World Duchenne Organization, Veenendaal, The Netherlands;
Email: imelda.degroot@worldduchenne.org.

©2025 De Groot IJM. This article is distributed under the terms of the Creative Commons Attribution 4.0 International License.

Key Words:

Accreditation
Duchenne Muscular Dystrophy
Program

Abstract

Nowadays it is common that a center specialized in a disease or type of diseases achieves an accreditation if they work according to the standards developed by the field. We developed an accreditation program for Duchenne muscular dystrophy specifically focussing on the care. We often hear the comment that centers state they are already accredited by a different organization. In this commentary we like to elucidate that there is a difference between all these accreditations. It depends on what the center wants when it applies for a specific type of accreditation.

Introduction

Recently we published an article on our Accredited Duchenne Centers Program: “Development of the accredited Duchenne centers program, a global program to achieve uniform and up-to-date care for all people living with Duchenne muscular dystrophy”¹. This program was started by the World Duchenne Organization, a worldwide patient organization with more than 50 international member organizations. The goal of the program is to have uniform and up to date care available worldwide. Duchenne muscular dystrophy, an X-linked genetic disorder, can be found worldwide with an incidence of 19.8 (95% CI:16.6-23.6) per 100,000 male births². Also females can be affected however in a lesser incidence. The disorder leads to loss of almost all skeletal muscle, pulmonic and cardiac muscle functions. The treatment of Duchenne muscular dystrophy is symptomatic as there is no cure as of yet. It is proven that good care can prolong life expectancy³. For Duchenne muscular dystrophy worldwide accepted standards of care and consensus statements are available^{4,5,6,7,8}. This is the base for the Accredited Duchenne Centers Program, as criteria on every aspect of care can be formulated and are therefore applicable worldwide. The program also looks at collaboration of the applying centers with peripheral centers in their region for shared care. In the program centers are visited and recommendations are formulated for each individual center to improve care and obtain accreditation or to refine care if the center is directly accredited.

Is another visitation necessary? We often hear that there are already so many visitations for all kinds of accreditation processes, and another one is too much or not necessary as “we are already accredited by another organization”. In this comment we like to

elucidate the differences between other accreditation processes and the Accredited Duchenne Centers Program. As an example we will use the European Reference Networks (ERN) accreditation, specifically the ERN EURO-NMD (NeuroMuscular Diseases) network⁹. This network aims at uniting “Europe’s leading experts to provide patients with access to specialist care through virtual and in-person consultations. The network aims to reduce time to diagnosis, improve diagnostic yield and increase access to appropriate care pathways.” As you can read, care is mentioned in their aims. Both programs screen for care. However, even though the two programs may look similar and centers often don’t feel the need to apply for both, there are significant differences between ERN EURO-NMD and ADC Program.

In the next paragraph we would like to explain the difference between both programs, what can help to explain if another visitation could be helpful.

Comparison of Accreditation Programs

There are a number of differences between the ERN EURO-NMD program and the Accredited Duchenne Care (ADC) program:

ERN is a European organization, with European formulated criteria, while ADC is a worldwide program with criteria that are applicable worldwide. In formulating the ADC criteria it has been taken into account that health systems are different between countries as are insurances.

ERN status is granted based on paper documentation. To become an ERN center one has to fill in the hospital characteristics including diagnostic facilities, number of patients per specific diagnosis, and a team profile. It is also requested to fill in publications (research). The ADC program focuses on the criteria formulated based on the international standards of care and consensus statements. Next to pre-visitiation questionnaires, which is the first screening to a possible accreditation status, a visitation team does live visits to the facility and talks to all the team members and to patients and their families to hear and see how they are working.

In the process of application to become an ERN member the opinion of the patients concerning this center is not evaluated. The ADC program involves patients and patient organizations several times. Before a visitation to a center is planned it is asked to send a letter of support of their national patient organization. Before the planned visitation the patient organization is asked to send a questionnaire based on the given care to their members, who are seen in the applying center. During the visitation the committee also speaks with patients and their families (without the presence of the health care providers).

The ERN application process is not specifically on one disease, ADC program focuses on Duchenne muscular

dystrophy which offers a more precise look into the care system and enables the committee to provide very specific comments and suggestions based on global experience the program gathers. The ADC program even looks at pediatric and adult teams/centers with different criteria.

ERN asks for yearly updates of the reported hospital characteristics and number of patients in the different neuromuscular diseases. The ADC program accreditation is for 5 years. Next to this it is obliged to stay up-to-date by following the Duchenne Care Conferences organized by the World Duchenne Organization on all kinds of topics to update knowledge in care.

Conclusion

In conclusion although care is in both organizations an aim, it is evaluated differently. Knowing whether a center has all the necessary team members does not mean the team is working according to the guidelines. If you want to see whether your center works up to date and according to the standards of care an evaluation at the site, talking to all the team members gives accreditation a specific guarantee for the center and for the patients and their families.

ERN is a virtual network. Their focus is on networks for experts (clinical and research) on rare diseases, where clinicians can find peers to discuss difficult diagnostic or therapeutic cases and researchers can discuss their programs. The ADC program has as yet not a network of accredited centers, although we hope to establish this in the future and collaboration is encouraged. The names of the accredited centers can be found on the ADC website and the website of the World Duchenne Organization.

A live visitation with both professionals and patients and their families gives a very good impression of how things work in a center. The patient questionnaires before the visitation can endorse the impression. If there are specific points for attention according to the outcomes of the questionnaires these can be discussed with the team of the center. Although the ADC program focuses on care, in a center that participated in clinical trials the experiences of the families can be helpful to get an impression of a team. Communication is a central part of the application and evaluation within the ADC program.

In our experience both parties, the visitation team and the team of the center, can learn from each other. To function within the health system of their country we have seen many bright solutions by the teams to achieve their goals. We can pass good practices as recommendations for other centers.

All the teams we have visited so far give as feedback that they have learned from the visitation to improve their care. And as it is a worldwide program, the ADC program allows a center to be compared in their care for persons with Duchenne muscular dystrophy to centers in other

countries. All accredited centers are mentioned on the ADC website, thus peer consultation is possible.

Education is yearly done by the World Duchenne Organization and as more centers become accredited a network for consultation is growing.

There are many programs available for centers around the world for accreditation or certification, think of JCI¹⁰ or IHI¹¹. But the focus of these programs can be quite different. For example JCI focuses on the procedures in a center, while IHI focuses more on the individual professionals and via this on health equity, the latter could coincide with the ADC program but is not a team evaluation. The ADC program focuses on whether the criteria of the guidelines and consensus statements are fulfilled, not on how they are achieved, and not on specific procedures in a center. This is therefore a distinction from the JCI accreditation.

Thus, as an overall conclusion to the question “are all these visitations and accreditations necessary?” the answer is: it depends on what you want to achieve.

References

1. De Groot IJM, Podolská K, Goemans N, et al. Development of the accredited duchenne centers program, a global program to achieve uniform and up-to-date care for all people living with duchenne muscular dystrophy. *Orphanet Journal of Rare Diseases* Orphanet J Rare Dis. 2025 Jul 2; 20(1): 335. doi: 10.1186/s13023-025-03843-9. PMID: 40604877.
2. Crisafulli Salvatore, Sultana Janet, Fontana Andrea, et al. Global epidemiology of Duchenne muscular dystrophy: an updated systematic review and meta-analysis. *Orphanet J Rare Dis* 2020 Jun 5; 15(1): 141. doi: 10.1186/s13023-020-01430-8.
3. Landfeldt E, Thompson R, Sejersen T, et al. Life expectancy at birth in Duchenne muscular dystrophy: a systematic review and meta-analysis. *Eur J Epidemiol.* 2020 Jul; 35(7): 643-653. doi: 10.1007/s10654-020-00613-8.
4. Birnkrant DJ, Bushby K, Bann CM, et al. DMD Care Considerations Working Group. Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis, and neuromuscular, rehabilitation, endocrine, and gastrointestinal and nutritional management. *Lancet Neurol.* 2018; 17(3): 251-267. doi: 10.1016/S1474-4422(18)30024-3.
5. Birnkrant DJ, Bushby K, Bann CM, et al. DMD Care Considerations Working Group. Diagnosis and management of Duchenne muscular dystrophy, part 2: respiratory, cardiac, bone health, and orthopaedic management. *Lancet Neurol.* 2018; 17(4): 347-361. doi: 10.1016/S1474-4422(18)30025-5.
6. Birnkrant DJ, Bushby K, Bann CM, et al. DMD Care Considerations Working Group. Diagnosis and management of Duchenne muscular dystrophy, part 3: primary care, emergency management, psychosocial care, and transitions of care across the lifespan. *Lancet Neurol.* 2018; 17(5): 445-455. doi: 10.1016/S1474-4422(18)30026-7.
7. Quinlivan R, Messer B, Murphy P, et al. ANSN. Adult North Star Network (ANSN): Consensus Guideline For The Standard Of Care Of Adults With Duchenne Muscular Dystrophy. *J Neuromuscul Dis.* 2021; 8(6): 899-926. doi: 10.3233/JND-200609.
8. Narayan S, Pietrusz A, Allen J, et al .ANSN. Adult North Star Network (ANSN): Consensus Document for Therapists Working with Adults with Duchenne Muscular Dystrophy (DMD) - Therapy Guidelines. *J Neuromuscul Dis.* 2022; 9(3): 365-381. doi: 10.3233/JND-210707.
9. European Reference Network, ERN EURO-NMD: <https://ern-euro-nmd.eu>.
10. Joint Commission International accreditation: www.jointcommission.org/en/accreditation.
11. Institute for Healthcare Improvement: www.ihl.org/learn/certifications.