Protocole National de Diagnostic et de Soins (PNDS)

Les maladies du spectre de la neuromyélite optique

Argumentaire

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Centre de Référence Maladies Inflammatoires Rares du Cerveau Et de la Moelle

MIRCEM
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Cet argumentaire a été élaboré par le centre de référence des Maladies Inflammatoires Rares du Cerveau Et de la Moelle (MIRCEM). Il a servi de base à l'élaboration du PNDS des maladies du spectre de la neuromyélite optique. Le PNDS est téléchargeable sur le site du centre de référence des MIRCEM : www.mircem.fr

Sommaire

Liste des abréviations

AQP4	Anticorps anti-aquaporine 4
BAFF	B-cell Activating Factor
LCR	Liquide Céphalo-Rachidien
NMOSD	Maladies du spectre de la neuromyélite optique
NO	Névrite Optique
PNDS	Protocole National de Diagnostic et de Soins
SEP	Sclérose En Plaques

Préambule

Le PNDS sur les maladies du spectre de la neuromyélite optique a été élaboré selon la « Méthode d'élaboration d'un protocole national de diagnostic et de soins pour les maladies rares » publiée par la Haute Autorité de Santé en 2012 (guide méthodologique disponible sur le site de la HAS : www.has-sante.fr). Le présent argumentaire est présenté sous forme de thématique.

Ce PNDS a été rédigé après une analyse approfondie et une synthèse critique de la littérature nationale et internationale par un groupe de travail pluridisciplinaire. Le document a été soumis à un groupe de relecture pluri-professionnel. Les remarques et suggestions issues des relectures ont été intégrées, discutées et validées par le groupe de rédaction permettant d'aboutir au document final. Le PNDS présenté est le résultat de ce travail collégial.

Argumentaire

Thème	Principales sources	Commentaires
Synthèse à destination du médecin traitant		
	• Wingerchuk DM, Lennon VA, Lucchinetti CF, Pittock SJ, Weinshenker BG. The spectrum of neuromyelitis optica. Lancet Neurol. 2007 Sep;6(9):805-15. • Wingerchuk DM, Banwell B, Bennett JL, Cabre P, Carroll W, Chitnis T, et al. International consensus diagnostic criteria for neuromyelitis optica spectrum disorders. Neurology. 2015 Jul 14;85(2):177‑89.	- Les critères internationaux de diagnostic des NMOSD de 2007 et 2015.
1. Introduction		
2. Objectifs du protocole national de diagnostic et de soins		
3. Diagnostic et évaluation initiale		
3.1 Objectifs		
3.2 Professionnels impliqués (et modalités de coordination)		
3.3 Circonstances de découverte / Suspicion du diagnostic		
L'atteinte visuelle : Névrite optique	• Wingerchuk DM, Banwell B, Bennett JL, Cabre P, Carroll W, Chitnis T, et al. International consensus diagnostic criteria for neuromyelitis optica spectrum disorders. Neurology. 2015 Jul 14;85(2):177‑89. • Toanen V, Vignal-Clermont C. Neuropathies optiques inflammatoires. //www.em-premium.com/data/traites/op/21-71372/ [Internet]. 2016 Nov 23 [cited 2020 Jul 19]; Available from: https://www-em-premium-	- Description des caractéristiques de l'examen clinique de NO dans les NMOSD. - Description de la spécificité de la poussée de NO de NMOSD par rapport aux autres causes de NMOSD. - Description de l'aspect clinique de NO au stade aigu. - Description du risque de récidive de NO en fonction de la séropositivité des anti-AQP4.

	com.sirius.parisdescartes.fr/article/1095381. • Matiello M, Lennon VA, Jacob A, Pittock SJ, Lucchinetti CF, Wingerchuk DM, et al. NMO-IgG predicts the outcome of recurrent optic neuritis. Neurology. 2008 Jun 3;70(23):2197–200. • Wingerchuk DM, Hogancamp WF, O'Brien PC, Weinshenker BG. The clinical course of neuromyelitis optica (Devic's syndrome). Neurology. 1999 Sep 22;53(5):1107–14. • Zhou H, Zhao S, Yin D, Chen X, Xu Q, Chen T, et al. Optic neuritis: a 5-year follow-up study of Chinese patients based on aquaporin-4 antibody status and ages. J Neurol. 2016 Jul 1;263(7):1382–9. • Kang H, Chen T, Li H, Xu Q, Cao S, Wei S. Prognostic factors and disease course in aquaporin-4 antibody-positive Chinese patients with acute optic neuritis. J Neurol. 2017 Oct;264(10):2130–40. • Van Nispen RM, Virgili G, Hoeben M, Langelaan M, Klevering J, Keunen JE, et al. Low vision rehabilitation for better quality of life in visually impaired adults. Cochrane Database Syst Rev. 2020 27;1. • Paolilo RB, Hacohen Y, Yazbeck E, Armangue T, Bruijstens A, Lechner C, Apostolos-Pereira SL, Martynenko Y, Breu M, de Medeiros Rimkus C, Wassmer E, Baumann M, Papetti L, Capobianco M, Kornek B, Rostásy K, da Paz JA, Ciccarelli O, Lim M, Saiz A, Neuteboom R, Marignier R, Hemingway C, Sato DK, Deiva K. Treatment and outcome of aquaporin-4 antibody–positive NMOSD. Neurol Neuroimmunol Neuroinflamm.	

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L'atteinte médullaire : myélite	• Collongues N, Papeix C, Zéphir H, Audoin B, Cotton F, Durand-Dubief F, et al. Nosology and etiologies of acute longitudinally extensive transverse myelitis. Rev Neurol (Paris). janv 2014;170(1):6‑12. • Kim S-M, Go MJ, Sung J-J, Park KS, Lee K-W. Painful tonic spasm in neuromyelitis optica: incidence, diagnostic utility, and clinical characteristics. Arch Neurol. août 2012;69(8):1026‑31. • Bradl M, Kanamori Y, Nakashima I, Misu T, Fujihara K, Lassmann H, et al. Pain in neuromyelitis optica--prevalence, pathogenesis and therapy. Nat Rev Neurol. sept 2014;10(9):529‑36. • Xiao L, Qiu W, Lu Z, Li R, Hu X. Intractable pruritus in neuromyelitis optica. Neurol Sci Off J Ital Neurol Soc Ital Soc Clin Neurophysiol. juin 2016;37(6):949‑54.	- Description du tableau clinique de l'atteinte médullaire. - Description du tableau clinique de l'atteinte motrice et son impact sur la qualité de vie. - Description du tableau clinique de l'atteinte sensitive de la myélite.
Syndrome de l'area postrema	• Paolilo RB, Hacohen Y, Yazbeck E, Armangue T, Bruijstens A, Lechner C, Apostolos-Pereira SL, Martynenko Y, Breu M, de Medeiros Rimkus C, Wassmer E, Baumann M, Papetti L, Capobianco M, Kornek B, Rostásy K, da Paz JA, Ciccarelli O, Lim M, Saiz A, Neuteboom R, Marignier R, Hemingway C, Sato DK, Deiva K. Treatment and outcome of aquaporin-4 antibody–positive NMOSD. Neurol Neuroimmunol Neuroinflamm. 2020 Jul 30;7(5):e837. • Shosha E, Dubey D, Palace J, Nakashima I, Jacob A, Fujihara K, et al. Area postrema syndrome: Frequency, criteria, and severity in AQP4-IgG- positive NMOSD. Neurology. 23 2018;91(17):e1642‑51.	- Description des symptômes de l'atteinte de l'*area postrema* et leurs importances afin de déterminer le diagnostic de NMOSD. - Description des risques d'extension de l'atteinte de l'*area postrema* sur la région bulbaire et la moelle cervicale. - Description de l'atteinte de l'*area postrema* chez l'enfant.

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Autres signes cliniques : Atteintes fréquentes ou classiques du NMOSD	• Shinoda K, Matsushita T, Furuta K, Isobe N, Yonekawa T, Ohyagi Y, et al. Wall-eyed bilateral internuclear ophthalmoplegia (WEBINO) syndrome in a patient with neuromyelitis optica spectrum disorder and anti-aquaporin-4 antibody. Mult Scler. 2011 Jul;17(7):885–7. • Kremer L, Mealy M, Jacob A, Nakashima I, Cabre P, Bigi S, et al. Brainstem manifestations in neuromyelitis optica: a multicenter study of 258 patients. Mult Scler. 2014;20(7):843–7. • Beigneux Y, Arnulf I, Guillaume-Jugnot P , Leu-Semenescu S, Maillart E, Lubetzki C, Benveniste O, Papeix C. Secondary Hypersomnia as an Initial Manifestation of Neuromyelitis Optica Spectrum Disorders. Multiple sclerosis and related disorders. 2020 Feb;38 :101869. • Baba T, Nakashima I, Kanbayashi T, Konno M, Takahashi T, Fujihara K, et al. Narcolepsy as an initial manifestation of neuromyelitis optica with anti-aquaporin-4 antibody. J Neurol. 2009 Feb;256(2):287–8. • Poppe AY, Lapierre Y, Melançon D, Lowden D, Wardell L, Fullerton LM, et al. Neuromyelitis optica with hypothalamic involvement. Mult Scler. 2005 Oct;11(5):617–21. • Pu S, Long Y, Yang N, He Y, Shan F, Fan Y, et al. Syndrome of inappropriate antidiuretic hormone	Description des symptômes classiques des atteintes aiguës du tronc cérébral et du diencéphale.

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Autres signes cliniques : Atteintes rares de NMOSD	• Jarius S, Lauda F, Wildemann B, Tumani H. Steroid-responsive hearing impairment in NMO-IgG/aquaporin-4-antibody-positive neuromyelitis optica. J Neurol. 2013 Feb;260(2):663–4. • Hage R, Merle H, Jeannin S, Cabre P. Ocular oscillations in the neuromyelitis optica spectrum. J Neuroophthalmol. 2011 Sep;31(3):255–9. • Takai Y, Misu T, Nakashima I, Takahashi T, Itoyama Y, Fujihara K, et al. Two cases of lumbosacral myeloradiculitis with anti-aquaporin-4 antibody. Neurology. 2012 Oct 23;79(17):1826–8. • Eichel R, Meiner Z, Abramsky O, Gotkine M. Acute disseminating encephalomyelitis in neuromyelitis optica: closing the floodgates. Arch Neurol. 2008 Feb;65(2):267–71. • Magaña SM, Matiello M, Pittock SJ, McKeon A, Lennon VA, Rabinstein AA, et al. Posterior reversible encephalopathy syndrome in neuromyelitis optica spectrum disorders. Neurology. 2009 Feb 24;72(8):712–7. • Clardy SL, Lucchinetti CF, Krecke KN, Lennon VA, O'Toole O, Weinshenker BG, et al. Hydrocephalus in neuromyelitis optica. Neurology. 2014 May 20;82(20):1841–3. • Close LN, Zanaty M, Kirby P, Dlouhy BJ. Acute Hydrocephalus Resulting from Neuromyelitis Optica: A Case Report and Review of the Literature. World Neurosurg. 2019 Sep;129:367–71. • Suzuki N, Takahashi T, Aoki M, Misu T,	Description des autres symptômes rares de NMOSD.

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Les anticorps anti-aquaporin 4 (AQP4)	• Wingerchuk DM, Banwell B, Bennett JL, Cabre P, Carroll W, Chitnis T, et al. International consensus diagnostic criteria for neuromyelitis optica spectrum disorders. Neurology. 2015 Jul 14;85(2):177‐89.	Description du rôle important joué par les anticorps AQP4 dans le cadre de l'établissement du diagnostic de NMOSD.

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L'imagerie	Wingerchuk DM, Lennon VA, Lucchinetti CF, Pittock SJ, Weinshenker BG. The spectrum of neuromyelitis optica. Lancet Neurol. 2007 Sep;6(9):805-15.	Description de l'imagerie dans les NMOSD.
L'étude du liquide céphalo-rachidien	• Wingerchuk DM, Lennon VA, Lucchinetti CF, Pittock SJ, Weinshenker BG. The spectrum of neuromyelitis optica. Lancet Neurol. 2007 Sep;6(9):805-15. • Sellner J, Boggild M, Clanet M, Hintzen RQ, Illes Z, Montalban X, Du Pasquier RA, C H Polman CH. EFNS guidelines on diagnosis and management of neuromyelitis optica. Eur J Neurol. 2010 Aug;17(8):1019-32.	Description des caractéristiques de référence du LCR dans les NMOSD.
3.5 <u>Les diagnostics différentiels</u>		
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3.6 Recherche de comorbidités		
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3.7 Recherche de contre-indications au traitement		
3.8 Annonce du diagnostic et information du patient		
4. Prise en charge thérapeutique :		
4.1 Objectifs		
4.2 Professionnels impliqués (et modalités de coordination)		
4.3 Prise en charge thérapeutique (pharmacologique et autre)		

Gestion de la poussée chez un patient dont le diagnostic d'une NMOSD est déjà posé	• Watanabe S, Misu T, Miyazawa I, Nakashima I, Shiga Y, Fujihara K, Itoyama Y. Low-dose corticosteroids reduce relapses in neuromyelitis optica: a retrospective analysis. Mult Scler. 2007 Sep;13(8):968-74. • Bonnan M, Valentino R, Olindo S, Mehdaoui H, Smadja D, Cabre P. Plasma exchange in severe spinal attacks associated with neuromyelitis optica spectrum disorder. Mult Scler. 2009 Apr;15(4):487-92. • Merle H , Olindo S, Jeannin S, Valentino R, Mehdaoui H, Cabot F, Donnio A, Hage R, Richer R, Smadja D, Cabre P. Treatment of optic neuritis by plasma exchange (add-on) in neuromyelitis optica. Arch Ophthalmol. 2012 Jul;130(7):858-62. • Kleiter I , Gahlen A , Borisow N , Fischer K, et al. Neuromyelitis optica: Evaluation of 871 attacks and 1,153 treatment courses. Ann Neurol. 2016 Feb;79(2):206-16. • Bonnan M , Valentino R , Debeugny S , Merle H, Fergé JL , Mehdaoui H , Cabre P. Short delay to initiate plasma exchange is the strongest predictor of outcome in severe attacks of NMO spectrum disorders. J Neurol Neurosurg Psychiatry. 2018 Apr;89(4):346-351. • Trebst C, Jarius S, Berthele A, et al. Update on the diagnosis and treatment of neuromyelitis optica: recommendations of the neuromyelitis optica study group (NEMOS). J Neurol 2014;261:1–16. • Ipe TS, Raval JS, Fernando LP, et al. Therapeutic plasma exchange for neuromyelitis optica spectrum disorder: A multicenter	- L'initiation des échanges plasmatiques, comme techniques thérapeutiques à suggérer, dans la prise en charge du patient adulte après la survenue d'une poussée. - Recommandations concernant l'utilisation des corticoïdes chez l'enfant et l'adulte. - Suggestions concernant l'utilisation d'autres traitements thérapeutiques dans la gestion de la poussée chez l'enfant.

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Cas particulier de la prise en charge thérapeutique de la première poussée de neuromyélite optique		
Traitement de fond de la maladie : Les anti-lymphocytes B (anti-CD20 et anti-CD19)	• Paolilo RB, Hacohen Y, Yazbeck E, Armangue T, Bruijstens A, Lechner C, Apostolos-Pereira SL, Martynenko Y, Breu M, de Medeiros Rimkus C, Wassmer E, Baumann M, Papetti L, Capobianco M, Kornek B, Rostásy K, da Paz JA, Ciccarelli O, Lim M, Saiz A, Neuteboom R, Marignier R, Hemingway C, Sato DK, Deiva K. Treatment and outcome of aquaporin-4 antibody–positive NMOSD. Neurol Neuroimmunol Neuroinflamm. 2020 Jul 30;7(5):e837. • Kim SH, Huh SY, Lee SJ, Joung A, Kim HJ. A 5-year follow-up of rituximab treatment in patients with neuromyelitis optica spectrum disorder. JAMA Neurol. 2013 Sep 1;70(9):1110-7. • Zéphir H , Bernard-Valnet R , Lebrun C , Outteryck O, Audoin B, et al. Rituximab as first-line therapy in neuromyelitis optica: efficiency and tolerability. J Neurol. 2015 Oct;262(10):2329-35. • Mealy MA, Wingerchuk DM, Palace J, Greenberg BM, Levy M. Comparison of relapse and treatment failure rates among patients with neuromyelitis optica: multicenter study of treatment efficacy. JAMA Neurol. 2014 Mar;71(3):324-30. • Torres J, Pruitt A, Balcer L, et al. Analysis of the	- Description de l'efficacité du rituximab par rapport à d'autres immunosuppresseurs. - Description d'une élévation du taux d'anticorps anti-AQP4, associée à une augmentation de la cytokine BAFF, chez plusieurs patients, 2 semaines après la première injection de rituximab, pouvant parfois expliquer l'aggravation sous rituximab. - Description de l'efficacité de l'inébilizumab dans la survenue de nouvelles poussées de NMOSD. - Description de l'efficacité de l'ofatumumab dans le traitement de la NMOSD associée à des anticorps anti-AQP4 en cas d'intolérance au rituximab. - Recommandation concernant l'utilisation du rituximab comme traitement de première intention ou de recours.

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5. Suivi		
5.1 Objectifs		
5.2 Professionnels impliqués (et modalités de coordination)		
5.3 Rythme et contenu des consultations		
5.4 Examens complémentaires		

5.5 Grossesse		
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5.6 Transition		
6. Accompagnement médico-social		
6.1 Accès aux soins et aux droits		
6.2 Les aides et l'accompagnement spécifiques des enfants		
6.3 Les aides et l'accompagnement spécifiques des étudiants		
6.4 Les aides et l'accompagnement spécifiques des adultes		
6.5 Recommandations particulières à destination des structures sociales, médico-sociales et scolaires		
6.6 Recommandations pour le remplissage des dossiers destinés à l'évaluation du handicap ou de la perte d'autonomie de la personne atteinte de NMO		
6.7 Contacts et autres informations utiles		

Annexe 1. Recherche documentaire et sélection des articles

Recherche documentaire

Sources consultées	Bases de données : PUBMED Sites internet : PUBMED
Période de recherche	Non limitée dans le temps
Langues retenues	Anglais et français
Mots clés utilisés	Neuromyelitis, neuromyelitis optica, NMOSD
Nombre d'études recensées	> 300
Nombre d'études retenues	106

Critères de sélection des articles

Selon le type de la publication et le thème traité.

Annexe 2. Liste des participants

Ce travail a été coordonné par le Pr Kumaran Deiva, coordonnateur du Centre de Référence des Maladies Inflammatoires Rares du Cerveau Et de la Moelle (MIRCEM) et le Pr Romain Marignier, responsable du site constitutif MIRCEM de Lyon.

Ont participé à l'élaboration du PNDS :

Groupe multidisciplinaire rédactionnel

- Pr Kumaran Deiva, neuropédiatre, CHU Kremlin Bicêtre
- Pr Romain Marignier, neurologue, Hospices Civils de Lyon
- Dr Caroline Papeix, neurologue, CHU Pitié-Salpêtrière
- Dr Hélène Maurey, neuropédiatre, CHU Kremlin Bicêtre
- Dr Jonathan Ciron, neurologue, CHU Toulouse
- Dr Nicolas Collongues, neurologue, CHRU Strasbourg
- Dr Emmanuel Cheuret, neuropédiatre, CHU Toulouse
- Pr Bertrand Audoin, neurologue, Hôpital de la Timone
- Pr Hélène Zephir, neurologue, CHU Lille
- Dr Elisabeth Maillart, neurologue, CHU Pitié-Salpêtrière
- Dr Pierre Meyer, neuropédiatrie, CHU de Montpellier
- Pr Sandra Vukusic, neurologue, Hospices Civils de Lyon
- Pr Muriel Doret-Dion, gynécologue, obstétricien, Hospices Civils de Lyon
- Dr Julie Pique, neurologue, Hospices Civils de Lyon
- Mme Evelyne Yver, assistante sociale, CHU Kremlin Bicêtre
- Mme Carole Lattaud, assistante sociale, CHU Pitié Salpêtrière
- M. Ala-Eddine Allouche, chef de projet MIRCEM, CHU Kremlin Bicêtre

Groupe de relecture

- Pr Sylvie Nguyen The Tich, neuropédiatre, CHU Lille
- Dr Nafissa Mamoudjy, neuropédiatre de ville, Saint-Maurice
- Dr Marie Thérèse Abi Warde, neuropédiatrie, CHU Strasbourg
- Dr Bertrand Bourre, neurologue, CHU Rouen
- Dr Marie-Caroline Pouget, médecin physique réadaptateur, Hospices Civils de Lyon
- Pr Caroline Froment Tilikete, neurologue, neuro-ophtalmologue, Hospices Civils de Lyon
- Pr Jérôme De Sèze, neurologue, CHU Strasbourg
- Mme Anne-Colombe Debroise, psychologue, CHU Kremlin Bicêtre
- Mme Marine Gelé, infirmière, Hospices Civils de Lyon
- Mme Christelle Berthier-Maillard, patiente et membre de l'association NMO France
- Mme Souad Mazari, responsable de l'association NMO France

Gestion des intérêts déclarés

Tous les participants à l'élaboration du PNDS sur les maladies du spectre de la neuromyélite optique ont rempli une déclaration d'intérêt. Les déclarations d'intérêt sont en ligne et consultables sur le site internet du centre de référence des maladies inflammatoires rares du cerveau et de la moelle (www.mircem.fr) et sur le site internet de la filière de santé maladies rares BRAIN-TEAM (www.brain-team.fr).

Les déclarations d'intérêt ont été analysées et prises en compte, en vue d'éviter les conflits d'intérêts, conformément au guide HAS « Guide des déclarations d'intérêts et de gestion des conflits d'intérêts » (HAS, 2010).

Modalités de concertation du groupe de travail multidisciplinaire

Réunions par visioconférence : 15/09/2020, 13/10/2020 et 03/12/2020.
Réunion téléphonique : 02/10/2020.
Nombreux échanges par e-mails.

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