

**JDM working group research / collaborative working document**  
**[January 2020]**

The following document lists current / proposed research studies, collaborative working and educational resources. If you would like to add anything to this document, please contact the JDM working group secretary (Meredyth Wilkinson) or Chair (Liza McCann):  
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**Research projects / collaborative working**

	<b>Project</b>	<b>Inclusion</b>	<b>Contact</b>
1	To audit the implementation of SHARE guidelines and determine current practice in Europe.	All members of JDM Working Group & EMERGE	Liza McCann / Charris Papadopoulou: <ul style="list-style-type: none"> <li>• liza.mccann@alderhey.nhs.uk</li> <li>• Charalampia.Papadopoulou@gosh.nhs.uk</li> </ul>
2	Extension of SHARE consensus for management of JDM in North America: IMACS project.	IMACS SHARE working group (open invite)	Susan Kim / Adam Huber / Annet van Royen-Kerkof <ul style="list-style-type: none"> <li>• Susan.Kim@ucsf.edu</li> <li>• Adam.huber@iwk.nshealth.ca</li> <li>• a.vanroyen@umcutrecht.nl</li> </ul>
3	Evaluation of patient / parent reported outcome measures in JDM: JDMAR / PROMIS tools	Project in development – will be open to all members	Angelo Ravelli / Kaveh Ardalan / Silvia Rosina / Liza McCann <ul style="list-style-type: none"> <li>• Angeloravelli@gaslini.org</li> <li>• Kaveh.ardalan@duke.edu</li> <li>• silviarosina@gaslini.org</li> <li>• Liza.mccann@alderhey.nhs.uk</li> </ul>
4	Study of quality of sleep in JDM (including fatigue)	Project in development – will be open to all members	Charris Papadopoulou / Judith Wienke <ul style="list-style-type: none"> <li>• Charalampia.Papadopoulou@gosh.nhs.uk</li> <li>• J.Wienke@umcutrecht.nl</li> </ul>
5	Promote education and training in JDM, including PReS / EULAR course and other learning resources which may include resources for patients and parents.	EMERGE members / patient and parent groups	Raquel Campanilho-Marques: <ul style="list-style-type: none"> <li>• raquelpcmarques@gmail.com</li> </ul>
6	Promote collaboration / core dataset entry in myositis registries,	Document to be available on website	Liza McCann / Lucy Wedderburn <ul style="list-style-type: none"> <li>• Liza.mccann@alderhey.nhs.uk</li> <li>• l.wedderburn@ucl.ac.uk</li> </ul>

	including use of Euromyositis.		
7	Consider standardisation of testing for myositis specific antibodies and / or education around MSAs	Current focus on education	Raquel Campanilho-Marques: <ul style="list-style-type: none"> <li>• raquelpcmarques@gmail.com</li> <li>• Working with Liza McCann, Sarah Tansley, Neil McHugh.</li> </ul>
8.	In collaboration with Health Professionals in Paediatric Rheumatology (HPPR) and IMACS interest group Rehab and exercise: Exercise training in JDM.	In development	Sue Maillard: sue.maillard@gosh.nhs.uk
9.	Develop / validate other outcome measures for JDM, including PROMs and Skin Disease Activity Scores		Raquel Campanilho-Marques / Beverley Almeida <ul style="list-style-type: none"> <li>• raquelpcmarques@gmail.com</li> <li>• Beverley.almeida@alderhey.nhs.uk</li> </ul>
10	Clinical care of calcinosis	All members of working group	Clarissa Pilkington <ul style="list-style-type: none"> <li>• Clarissa.Pilkington@gosh.nhs.uk</li> </ul>
11.	Multinational study on current outcomes of children with JDM	Proposal from PReS Working party	Angelo Ravelli & other members of the working group.
12	JDM Biomarker project		Annet van Royen-Kerkof / Rebecca Nicolai / Brigitte Bader Meunier <ul style="list-style-type: none"> <li>• a.vanroyen@umcutrecht.nl</li> <li>• Rebecca.nicolai@opbg.net</li> <li>• brigitte.bader-meunier@aphp.fr</li> </ul>
13	JDM and deregulated interferon signaling: From cellular mechanism to improved patient management	ERC application	Mathieu Paul Roderio / Brigitte Bader Meunier <ul style="list-style-type: none"> <li>• m.roderio@uq.edu.au</li> <li>• brigitte.bader-meunier@aphp.fr</li> </ul>

### **Educational links / resources in JDM:**

<b>Resource</b>	<b>Information</b>	<b>Link</b>
<b>EULAR/ PReS JDM online training module</b> – part of the EULAR/PReS Online Course in paediatric Rheumatology	Aimed at paediatric rheumatologists at the start of their training, paediatricians with an interest in rheumatology and adult rheumatologists that want to increase paediatric rheumatology knowledge	<a href="https://www.pres.eu/activities/scientific-and-educational-instruments-and-tools.html">https://www.pres.eu/activities/scientific-and-educational-instruments-and-tools.html</a>
<b>Fellowships</b> – to allow training in a different centre	Aimed at young clinicians or researchers who are interested in doing a fellowship in a different centre	<a href="https://www.pres.eu/activities/young-investigators/fellowship-programs.html">https://www.pres.eu/activities/young-investigators/fellowship-programs.html</a>
<b>IMACS tools</b> – available to members of IMACS (free to join and new members welcome)  <a href="https://www.niehs.nih.gov/research/resources/imacs/index.cfm">https://www.niehs.nih.gov/research/resources/imacs/index.cfm</a>	IMACS has opened an area on the members' website to view the training tools for the disease assessment measures (disease activity, disease damage and other tools). Following viewing of each pdf or video file, a training certificate is issued. The aim is to enhance training on various assessment tools and also presentation of completion of training for use in clinical studies and therapeutic trials.	<a href="https://connect.niehs.nih.gov/imacs/module/training?tab=0">https://connect.niehs.nih.gov/imacs/module/training?tab=0</a>  <a href="https://connect.niehs.nih.gov/imacs/module/training?tab=1">https://connect.niehs.nih.gov/imacs/module/training?tab=1</a>  <a href="https://connect.niehs.nih.gov/imacs/module/training?tab=2">https://connect.niehs.nih.gov/imacs/module/training?tab=2</a>
<b>PReS mentorship program</b>	A new mentorship program will be starting in 2020.	Refer to PReS website or contact EMERGE group leads

### **Previous projects achieved:**

- Consensus Based Recommendations for the Management of Juvenile Dermatomyositis (SHARE recommendations) for diagnosis and treatment of JDM [Bellutti Enders F et al, Ann Rheum Dis. 2017; 72(2):329-340]
- Criteria for Minimal, Moderate, and Major Clinical Response for Juvenile Dermatomyositis: An ACR/EULAR/IMACS/PRINTO Collaborative Initiative [Rider LG et al, A&R 2017, 76(5): 782-791].
- Development of a consensus core dataset in JDM for clinical use to inform research. Collaborative initiative including members of PReS working party, PRINTO Centre Directors, and members of IMACS, CARRA, UK JDRG and patient/parent groups (Myositis UK and Cure JM). [McCann LJ et al, Ann Rheum Dis 2018, 77(2):241-250]
- Collaboration with Euromyositis, including writing and promoting the use of JDM webpages for the Euromyositis registry. <https://euromyositis.eu/>
- Sharing knowledge on projects relevant to all members including the development of an internationally agreed biopsy scoring tool (Varsani H et al, Ann Rheum Dis 2015;74(1)204-210), an MRI-based scoring system in JDM (Thyoka M et al, Rheumatology 2018; 57(9)1661-1668), the JDM multidimensional assessment report, JDMAR (Varnier GC, Pediatr Rheumatol Online J 2013), Outcome measures JDM. (A. Ravelli / S. Rosina): JDMAI, composite disease activity score (PMID: 30690571) and hybrid MMT-8/CMAS (hMC), PMID: 29245175
- PReS/ EULAR JDM module; part of the online course in Paediatric Rheumatology [https://www.eular.org/edu\\_online\\_course\\_paediatric.cfm?showArchive=1](https://www.eular.org/edu_online_course_paediatric.cfm?showArchive=1)