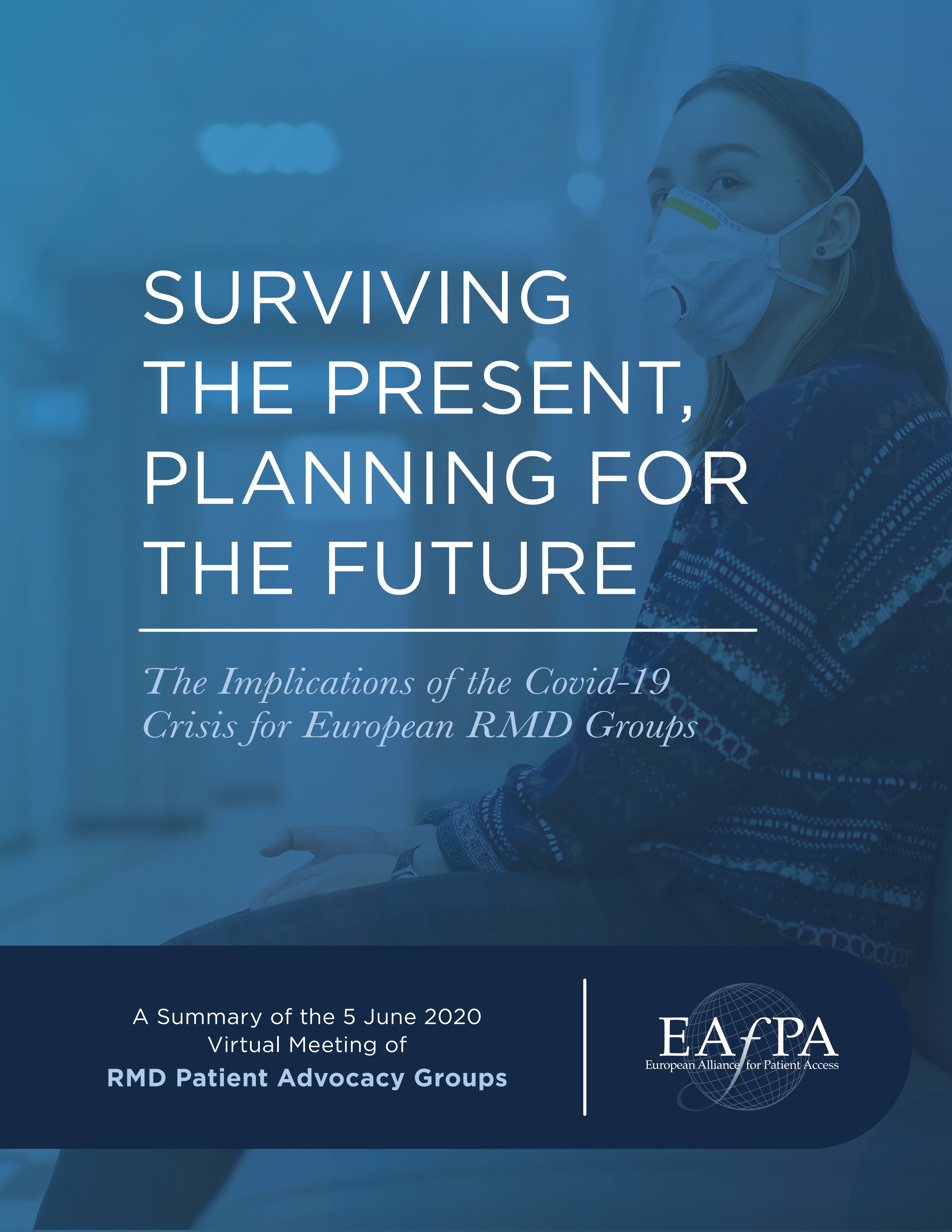

SURVIVING THE PRESENT, PLANNING FOR THE FUTURE

The Implications of the Covid-19 Crisis for European RMD Groups

A Summary of the 5 June 2020
Virtual Meeting of
RMD Patient Advocacy Groups

EAfPA
European Alliance for Patient Access

On 5 June 2020, in a Related Meeting of the EULAR Congress, the European Alliance for Patient Access (EAfPA) welcomed delegates to an online meeting of rheumatic and musculoskeletal disease, or RMD, patient advocacy groups.

Presenters & Topics

Neil Betteridge

Strategic Advisor, European Alliance for Patient Access (EAfPA), welcomed delegates to the meeting. The meeting's objective was twofold:

- To bring the RMD patient advocacy group community together to consider the impact of, and response to, COVID-19 at the global, European and national levels
- To consider how we can optimise the lessons learned so far, to serve our communities in the coming months and years to advocate for the needs of people with RMDs.

Brian Kennedy

Executive Director, Global Alliance for Patient Access (GAfPA), gave an update on the work of GAfPA. It had been another busy year and, with the global impact of the pandemic, GAfPA was uniquely placed to assimilate the views of key stakeholders in health from across all continents to identify common and diverse challenges or opportunities going forward.

Professor Anthony Woolf

Past Chair of the Global Alliance for Musculoskeletal Health (G-MUSC), presented on "Influencing Policy Recommendations."

Prof Woolf described some of the current health challenges facing policymakers. These include:

- Increased longevity resulting in ageing populations and people living longer but not healthier lives
- Unhealthy lifestyles, obesity & physical inactivity
- Accumulating multi-morbidity
- Inequality in access to health care
- The need to address health and social care costs.

The World Health Organization is considering the development of a global framework on RMDs, and G-MUSC would be consulting stakeholders in the coming period.

Annette de Thurah

Associate Professor, Dept. of Clinical Medicine, University of Aarhus, Denmark, and former Chair of EULAR Health Professionals in Rheumatology, provided the keynote presentation, The Future of Telecare.

In the Danish model, which Prof. de Thurah has described in various journals, a traffic light system has been used in telecare to support effective triage in rheumatoid arthritis patients. Patient education in the process has been vital, from holding focus group interviews to literature research covering informational and educational needs to involving patients in the development of all aspects of the project.

Clare Jacklin

CEO, National Rheumatoid Arthritis Society (UK)

&

Dieter Wiek

Deutsche Rheuma-Liga (Germany), both presented from a national perspective on how COVID-19 has impacted patient advocacy groups.

Each described how their organisations have adapted to the challenges of the COVID-19 crisis, in terms of:

- Meeting the huge demand for new information
- Rising to the challenges of fundraising in increasingly difficult times
- Advising on safe exercise during lockdown
- Clarifying the employment rights of people with RMDs
- Determining how to most effectively influence policy through advocacy at such a critical time.

A lively discussion ensued, including updates on related issues from Francoise Alliot Launois, AFLAR, France; Ugo Viora, ANMAR, Italy; and Souzi Makri from CYPLAR, who is EULAR PARE Chair Elect. Souzi fed back to the meeting from the EULAR Congress session where she had presented on the information needs of people with RMDs in the time of crisis.

KEY THEMES

The following issues were raised by participants during the online discussion.

Making Use of Evidence

The burden of RMDs is not sufficiently reflected in policy and services, yet evidence shows that the burden of disability in RMDs outweighs that of other major disease areas, such as mental health.

Prevention is key and models of care exist to illustrate this, but advocacy is needed to embed this approach in policy.

Access

COVID-19 is already diverting resources away from long-term conditions. We need to take advantage of other hooks and look for opportunities: "Look to the unhealthy lifestyles, age, multi-morbidities, inequality agendas. We need to push the long-term saving benefits of addressing RMDs".

Given the diversion of RMD drugs to COVID-19, there is a challenge to make sure there are sufficient supplies for people with RMDs. Diversion of non-pharmacological therapies is also an issue, e.g. in physiotherapy. Access to prescriptions has been an issue for many people with RMDs, and it continues to pose a challenge during the pandemic.

Participants agreed that telecare is not recommended for everyone in all settings. For example, undiagnosed or newly diagnosed people – anyone with active or uncontrolled symptoms – should still be seen face to face. In addition, patients who are overly positive about their symptoms might slip through the net if not seen in person. Validated algorithms can help safeguard against this, flagging people in greater need of face-to-face support so that they get prioritised.

There were worries that telecare could exacerbate health inequalities due to the cost of internet connections and devices, though not all telecare needs smartphones or computers. Much is done via phone conversations. It was agreed that patients should help determine which model of care suits them.

Coalitions and Collaborations

There has been increased collaboration between RMD patient advocacy groups, scientific groups and health professionals in rheumatology during the pandemic to ensure trusted and consistent information gets to people with RMDs. There are benefits of building a coalition to develop a community representing people with RMDs, clinicians, family, policymakers and employers, a community with representatives from across the life stages, including young people.

Relationships with industry and other funders have been frank during this time. Some patient advocacy groups have successfully secured emergency funding to carry them through this time. There is a need for industry to recognise the impact of COVID-19 on patient advocacy groups as they need to plan their priorities and services going forward.

Coming Out of Lockdown

The loosening of lockdown has laid bare challenges involving the emotional and safety impact on people with RMDs. There are also practical issues for patient advocacy groups regarding the resumption of services, especially face-to-face services. Examples include how to restart some direct services such as water therapies, which can be a key source of income and will cause financial difficulties if they cannot resume.

Opportunities

The pandemic has shown the necessity of keeping dialogue going with members and other people with RMDs so they get access to the most up-to-date information and support. This has had to be mostly virtual. Patient advocacy groups have had to keep pace and adapt to the "new needs" of the patients they serve.

For example:

- National Rheumatoid Arthritis Society launched a service called "Here for you". They gave online training to telephone volunteers to talk to people who were calling the organisation and wanted to talk about being isolated, taking medications, etc.
- As illustrated by the Deutsche Rheuma-Liga's presentation, organisations have typically set up COVID-19 pages within their website to provide up-to-date information to members.

There was recognition that the crisis has meant that people who may never have "video chatted" before have embraced video technology due to keeping in touch with families during isolation. Meeting participants asked: Will the onus now be on patient advocacy groups to upskill patients in the use of IT to reduce the risk of a growing digital divide?

Patient advocacy groups can support rheumatology clinics in telecare development in a number of ways, including:

- Helping to ensure that patients at the point of diagnosis first have an in-person visit, and only subsequently use telecare to continue care.
- If patients use telecare, they still need to be “prepared” for their visit.
- Allowing people who are reluctant to use technology to still have a positive patient experience. Even reluctant patients might appreciate a phone consultation.

Developments in telecare are now leading to new e-learning platforms for people with RMDs, such as podcasts and quizzes, to deepen learning about the condition and its care.

CONCLUSION

In closing, ***Brian Kennedy, Executive Director, Global Alliance for Patient Access*** thanked all speakers and participants for their contributions at such a challenging period for everyone, and to Sanofi for supporting this meeting.

GAfPA agreed to produce materials based on the content of the discussion, which all organisations in the RMD community would be welcome to use in support of their national advocacy efforts. Delegates were also reminded that, if they have specific access issues in their country relating to patients’ rights to care and approved therapies, they can contact Neil Betteridge at EAfPA, who will provide any support that EAfPA can offer.

The meeting provided a valuable opportunity for patient groups across geopolitical divides to share insights and strategies for best serving people living with RMDs. As COVID-19 continues to present challenges, patient advocacy groups will likewise continue working together to increase patient education and to further policies that allow for continued, optimal and patient-centred care.

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EAfPA
European Alliance for Patient Access

About the European Alliance for Patient Access

The European Alliance for Patient Access is a division of the Global Alliance for Patient Access,an international platform for health care providers and patient advocates to inform policy dialogue about patient-centered care.

GAfPA.org