13 October 2021

Save our Sons Duchenne Foundation Submission:

To:
The Senate Standing Community on Community Affairs Inquiry Into the Provision of General Practitioner GP and related primary health services to outer metropolitan, rural and regional Australians.

"I have been to emergency with my son and had to give the Doctor a quick lesson on DMD at 2am in the morning. I literally had to spell out the name of the condition ("D…U….C…H…') and suggest that he look up the fact sheets or contact Westmead – which of course, took longer and was stressful. My son had chest pains and was exhausted and anxious, so I was less than thrilled with the whole situation"

Mother of a son with Duchenne living in a rural location.

Introduction:

The Save Our Sons Duchenne Foundation (SOSDF) thanks the Senate Standing Committee on Community Affairs ("the Committee") for the opportunity to provide a submission to the Committee on the Inquiry ("the Inquiry) which is reviewing the provision of general practitioner (GP) and related primary health services to outer metropolitan, rural and regional Australia.

This submission will not attempt to address all of the Inquiry Terms of reference but rather, will be making a few broad comments which are primarily going to the Terms of Reference of **a, c** and **d** as they appeared on the Inquiry website.

Consultation timeframe:

While SOSDF greatly appreciates the two week extension which was granted to our organisation for purposes of preparing this submission, we have nonetheless been concerned about the brevity of the consultation period provided for the Inquiry. It was only on the 4 August 2021 that the Senate referred the Inquiry to the Committee, yet the official close-off date for submissions was only a few weeks later at the end of September 2021. This we believe was inadequate given the Inquiry subject matter and doubtless has left many stakeholders (including stakeholders in our community) with insufficient time for meaningful participation in the Committee's work.

SOSDF would therefore recommend that where possible, more time be allocated to allow further community consultation/engagement as this Inquiry processes unfolds.

Our experience with important Inquiries of this nature (for example, the recent Federal Parliamentary Inquiry into approval processes for new drugs and medical technologies) has been, that some months are typically provided to ensure that all stakeholders and communities with an interest in the issues under review, have sufficient opportunity to provide input and feedback.

Unfortunately, on this occasion it did not appear to occur and that has compromised our organisation's ability to undertake a more thorough and comprehensive consultation process with the Duchenne and Becker muscular dystrophy community throughout Australia.

Be that as it may, we have still been able to have some invaluable conversations with community members around the subject matter of this Inquiry. Furthermore, in late 2020, SOSDF undertook a major consultation in relation to the [1]NSW Parliamentary Inquiry into the Regional, Rural and Remote health and hospital systems. Although this was a State based process, there are many parallels between this inquiry and this current Federal Inquiry with issues around GP and primary health services provision, common to both. On that basis, SOSDF will rely in large part on the findings of that broader state based consultation and will refer the Committee to our submission to the NSW Inquiry which is **attached** for your information.

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[1] Save our Sons Duchenne Foundation submission to the "NSW Upper House Inquiry into Health Outcomes and Access to Health and Hospital Systems in Rural, Regional and Remote NSW"

Who We Are?

The Save our Sons Duchenne Foundation is the peak body representing the Duchenne (DMD) and Becker (BMD) muscular dystrophy community in Australia. DMD and BMD are genetic and progressive muscle wasting conditions which affect 1 in every 3,500 boys and rare girls in this country. These conditions result in the loss of ambulation at a very young age and the continued decline in all muscle usage until sadly, untimely and premature death results.

Our organisation which has been in existence for over 12 years, is battling to find a cure for this debilitating and terrible condition. SOSDF has subsequently been instrumental in funding clinical trials, leading research projects and a neuromuscular and clinical nurse's program at several children's hospitals across Australia. In addition, the organisation has an established telehealth nursing service, develops a range of community programs/resources and is actively undertaking systemic advocacy work on behalf of the community we are representing. SOSDF is also responsible for establishing a range of innovative fundraising and marketing events which aim to not only raise money for important community initiatives and research, but also, to raise community awareness of the Duchenne and Becker conditions.

For more information on SOSDF and Duchenne and Becker muscular dystrophy please refer to our website at www.saveoursons.org.au. Please also refer to the **attached** videos at **Attachment One** which provide further insights into the disease and the work which our Foundation undertakes.

Overarching comments:

Duchenne and Becker muscular dystrophy are highly complex conditions which typically involve multiple medical interventions and treatments and from a range of GP services and allied health professionals. These interventions and treatments are frequent costly and ongoing over the different phases and lifespan of the disease.

Attachment 2 is a graphic representation of some of the care and neuromuscular requirements of these boys/young men.

Families and young men dealing with this disease are time poor as a consequence of managing the disease and the constant carer responsibilities which arise from it - including time going to and from various medical and allied health appointments. Families and young boys/men residing in outer metropolitan, rural and remote areas consequently need contact with GP and primary health services who not only understand DMD and BMD but are accessible, knowledgeable and working in sync with specialist (city) services and able to expedite issues in a timely and quality manner. Unfortunately, this is not often the case (and sometimes despite the best efforts of these GPS and others concerned) with many families residing outside major metropolitan areas feeling they are denied the quality of service which is required.

One mother with a son with Duchenne explained her experience in the following:

"Physical access to buildings where Dr practices are housed in the country can be a real issue. Many GP clinics are based in old houses in country towns which simply are not accessible…You don't get many GPs who are open to learning and you can't trust that you will be directed to the right treatment".

Another mother of a son with Duchenne from Northern Queensland stated:

*"Living in Mt Isa, we had a rural outreach from a centre of excellence in *Montrose treatment sanatorium, oversight from a neurologist at the Mater hospital in Brisbane and for a while outreach happened in Cairns until the GFC and later NDIS put an end to that.* ***The infrastructure needs to be re-established*** *as we lost so much therapy expertise when peak bodies shifted focus it is virtually non-existent in cities let alone further afield…….it is very dangerous to apply general principles to complex patients requiring specialized care and services and support for these medicos have to include: efficient patient transport for those with complex needs, outreach specialist support a couple of times a year, access to the equipment needed by chronic patients, local allied health expertise and especially access to the city specialists/consultant teams in each disease group to ensure real-time collaboration and support for any rural generalist who cannot move their patient temporarily."*

The financial, social and personal costs of Duchenne and Becker muscular dystrophy can be astronomical for families and young men with lived experience of DMD and BMD. In 2020, SOSDF commissioned the McKell Access Economics Institute to conduct research into a range of issues affecting the Duchenne and Becker communities in Australia. The final report (*"Living with Duchenne and Becker in Australia: Supporting Families Waiting for a Cure"*) is an **attachment** to this submission and highlighted amongst a number of issues, the following.

[2]*Duchenne in particular, is associated with significant lifetime health and social care costs. It is estimated that these can total up to $2.25 Million for a child living until their mid-thirties. In*

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[2] Mc Kell Access Economics Institute Report Pages 14, 44

addition, informal care costs total up to $630,000 in terms of reduced female participation in the workforce. However, the costs for a child living to their mid-thirties rise to $2.88 million.

Families who participated in the McKell research typically reported high out of pocket medical costs, ranging to $1800 per month.

While the NDIS has played a critical role in offsetting and defraying some medical costs, medical costs remain extremely high for the DMD and BMD community. These costs are simply compounded in rural and regional areas due to GP and primary health service shortages and the need for families to typically seek more specialist services and care in the city centres – involving transportation and accommodation costs, time away from the workplace, and costly absences from home, community and social life.

It is essential therefore, that Governments at all levels, Health Departments and medical stakeholders work together to ensure quality GP services and primary health services are available to rare disease communities such as DMD and BMD irrespective of particular postcodes and residential locations.

Specific Issues Going to the Terms of Reference:

Lack of GP and primary health care provider knowledge of rare diseases such as Duchenne and Becker: "*It's not Multiple Sclerosis*"

It can be hard enough at the best of times accessing GP's and primary health services in outer metropolitan rural and regional areas, but too often when these services are accessed our community raises concerns, that too few of these GPs have any knowledge or true understanding of what Duchenne and Becker muscular dystrophy entail.

This issue was highlighted in this current consultation but was also very evident in our discussion with families in rural, remote and regional areas who participated in our earlier NSW Inquiry consultation. A selection of statements from parents with sons with Duchenne and Becker is taken from our collective submission to that Inquiry and is reproduced below - these comments would doubtless be mirrored across the country.

"When he was 10, he fell over and went to hospital. I said he needed X rays. The Doctor just

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rolled his eyes. We ended up going to a regional hospital. He had fractured his back. Had I not advocated for him it would have been a very serious situation…" A North coast mother of a son with Duchenne recapping on her experiences with her local GP.

"Our endocrinologist called it "Doo-chen-ease" and admitted she hadn't seen it since uni" Mother of a Duchenne boy from Wagga Wagga.

"They sit there and go it's MS (multiple sclerosis) There didn't appear to be a real care plan dealing with boys from season to season. No preparation for winter. No overall road map with no pit stops for therapy". Father of a Duchenne boy on the South coast.

With limited knowledge of theses conditions, parents/carers report that they frequently must "educate" rural/regional GP's and other health professionals about the specific needs of their son/s. Furthermore, these parents/carers are constantly being forced to advocate to ensure that their child receives the best and most appropriate form of health care -adding to the already onerous advocacy and care burden which is placed on these (exhausted) families.

Explained one mother with a son with Duchenne:

"We had to do all the research and adjusting….. You have to be the expert and find professionals prepared for you to be the expert".

Delays in Diagnosis for Duchenne and Becker:

Another issue arising from the lack of GP training and education in Duchenne and Becker muscular dystrophy concerns the lack of early diagnosis of the condition, meaning that treatments can be delayed and family planning decisions compromised. [3]This was a common concern expressed in our earlier NSW Inquiry consultation, but it has also arisen during the course of this brief consultation. One Queensland mother with a son with Duchenne has suggested child health checklists utilised by GPs be changed so that parents are given the option of a blood test earlier:

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[3] [3] Save our Sons Duchenne Foundation submission to the "NSW Upper House Inquiry into Health Outcomes and Access to Health and Hospital Systems in Rural, Regional and Remote NSW" Pages 15-16

"*It would be great to change the child health checklists GPs use so parents are given the option of a blood test earlier e.g. test all kids with low muscle tone. The Gower's sign which is used in diagnosing these conditions, is not widely known by GPs and allied health professionals.*

The first thing our paediatrician said was "didn't your GP order a blood test?" GPs definitely need more education to avoid misdiagnosis and ensure earlier diagnosis. So many boys are told "low muscle tone" or similar conditions instead of doing 1 blood test for the CK level. We did intensive physio, gymnastics and swimming for years which have done more harm, pushing our son too hard, due to misdiagnosis. He was also delayed in starting steroids. There was a long wait to see a paediatrician, who then referred to the Children's Hospital specialists. Long waiting lists for specialists are an issue. Covid has resulted in a lot of mental health concerns for kids and young people, creating longer waiting lists for paediatric specialists".

GP Shortages and Turnover: "*Here Today and Gone Tomorrow*".

Compounding the issue of the lack of GP knowledge/training/experience in the rare disease conditions such as Duchenne and Becker muscular dystrophy, appears to be the acute shortage and high turnover of GP's working in the bush and remote locations - where some are based simply on a temporary basis or are using such locations as staging posts for bigger and "better" assignments.

Furthermore, it has been well documented in both news and research publications over several years, the structural, economic, professional and social difficulties and impediments/disincentives in attracting GPs to locations outside of our city centres. See for example [4]SBS news article "*Doctor Shortage leaving Australia's rural areas in crisis*" or the [5]ABC news article "*Rural Doctor Shortage could be solved if there were like these*". Note also for example [6]the Australian Institute of Health and Welfare Report on *Rural and Remote Health* which not only identified GP shortages in the bush, but the poor local health infrastructures of many rural and regional locations and the need for GP's and others to provide a broader range of services to a more widely distributed population. This report also highlighted that because there were fewer specialist services available in rural and remote areas that people living in these areas were more reliant on GPs.

This has profound implications not only for the general population but particularly for

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[4] SBS News 9 February 2019 www.sbs.com.au

[5] ABC News 14 March 2019 www.abc.net.au

[6] Australian Institute of Health and Welfare "Rural and Remote Health" 22 October 2019

rare disease communities such as Duchenne and Becker, who are highly reliant on specialist services/advice and high quality GP care and commitment.

As already highlighted, DMD and BMD are complex conditions which play out very differently for those who suffer from the condition. The importance of stable, ongoing relations with a GP and other health professionals who have a good understanding of the condition and the particular care needs of individuals, cannot be underestimated.

This can be illustrated in the contrast between the following two statements:

"My main concerns are the transient nature of some GPs-when ours retired it was really hard to find a new GP and took a long time to build understanding of the ongoing nature of our care needs ie. regular referral to specialists, repeat scripts and blood pressure checks, on top of normal visit requirements. We have been "reprimanded" for not requesting a long appointment when only seeking referrals and scripts (no physical examination of any kind required) -would have needed a long appointment with previous long standing GP as they were familiar with our requirements. Often as soon as we get comfortable the GP has suddenly moved on……" Mother of a son with Duchenne from South Western NSW.

"I have had one GP my entire life & he has great knowledge of Duchenne so I don't think I'll be much help with your consultation on GPs". Young man with Duchenne from Victoria.

Potential resolutions:

While SOSDF will recommend that there should be more training and education of GPs and other primary health providers in rare disease conditions such as Duchenne and Becker muscular dystrophy, (as part of GP training reforms) our community does recognise that DMD and BMD are just one of nearly [7]7,000 rare disease conditions across the globe. On that basis alone, it will be extremely difficult and impractical ensuring that GP training in Duchenne and Becker is able to be provided to all medical practitioners. SOSDF does believe however that more resources and materials could be developed for some GPs to equip them with greater knowledge and insights into DMD and BMD and rare conditions more generally.

The Committee should note that our community would be more than prepared to help in any efforts to deliver these resources and training packages.

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[7] https;//rarediseases.org "Rare Diseases Day: Frequently Asked Questions".

Further, our community which is a highly resilient and creative one, is always searching for possible solutions to complex problems (the daily barriers they face make this an absolute imperative). Not surprisingly, they have been prepared to suggest some strategies to address GP shortages and knowledge deficiencies in rural and remote locations.

Short of seeking greater Government intervention and funding to address current inequities, a proposal has been made that a specialist (and national) Duchenne/Becker medical team be established which can provide 24/7 support to families whenever they may be seeking specialist medical advice and support – and irrespective of their particular location. While such support would be telephone based, it could nonetheless provide an important adjunct/back up to direct medical services provided in regional and remote locations, and importantly during times of crisis or transition. This service would relieve many families of the care burden (and fatigue which results from it) and would help ensure that families and young men had access to advice and support from professionals who are grounded in, and knowledgeable of the Duchenne and Becker conditions.

A further suggestion comes from a mother of a Duchenne Boy in South Australia who proposes the development of greater collaboration/partnership and "shared care models" between GPs and specialists in DMD and BMD. She writes:

"People with chronic health conditions and rare diseases (e.g. DMD) typically have many ongoing appointments with multiple medical specialists as well as regular appointments with several allied health professionals, other therapy and support service providers, and their GP. These appointments take up a lot of time, impacting on work and school attendance, and in some cases resulting in loss of income for patients and their carers and sometimes impacting school attendance for siblings of paediatric patients. This time burden is made worse when patients/carers need to educate their GP on their rare condition, when the GP needs to consult with the specialist before being able to meet the patient's needs, and when more than one appointment is necessary because the GP has a limited understanding of the condition (e.g. to enable time to consult with the specialist if they're not contactable during the first appointment, or if the patient/carer needs to strongly advocate for their needs over multiple visits before the GP is prepared to act).

A shared-care model *between the medical specialists and GP would help to address these issues and would also result in reduced travel time for rural and remote patients by limiting how often the patient needed to travel to the city for specialist appointments. Instead of attending the specialist appointment in-person this session could be conducted via telehealth (video conference)* *at the GP clinic (with the GP present). The specialist could instruct the GP for any physical examinations required, and behavioural/functional observations would be possible via telehealth or the GP could complete these and provide live feedback to the specialist. This would ensure the GP had a good understanding of the treatment plan, an increased understanding of the health condition, would have the opportunity to raise any queries with the specialist, and help to ensure that everyone had a shared understanding of who was responsible for each component of the patient's care plan."*

<u>Travel/transportation/accommodation Issues: "*Bringing the Community to the Care*":</u>

With more limited health options available to the DMD/BMD community in regional and rural areas, families are often forced to travel long distances to obtain quality GP and specialist services.

Often this can involved interstate travel or travel involving great distances.

This is highlighted in the following statement from a mother of a young man with Duchenne who lives in a town which is nearly 400 kms from Adelaide.

"None of the specialists my son needs to see (cardiac and thoracic and endocrine once a year) also physiotherapist (local therapist has limited knowledge of Duchenne) visit our town so we have to go to Adelaide several times a year. Also for bone density scans (once a year) as my son has Osteoporosis from using steroids for his condition. Breathing tests are also in Adelaide these are once or twice a year depending on how he is going. Sleep studies are also in Adelaide and they are every 2 years. These trips to Adelaide are 4 hour trips each way. I have to take a day off work and I take another driver with me so they generally have to have a day off work as well. It's also a long time in the car with my son being bumped around as well due to poor road conditions in certain areas along the way".

The Save Our Sons Duchenne Foundation understands that most (if not all) State and Territories provide some form of travel and accommodation subsidy schemes for those persons who are required to travel long distances to obtain specialist services and medical support provided in the city. These schemes are critical for rare disease communities such as the Duchenne and Becker community who are living in regional and remote locations and who need to travel to the major metropolitan centres for specialist care.

While these travel schemes such as the Isolated Patients Travel and Accommodation Assistance scheme (IPTAAS) in NSW are a State Government responsibility, SOSDF argues that these schemes should be a focus of the current Senate Inquiry as these schemes are central to quality of health care access – inclusive issues of GP and primary health services provision. If GP and primary health services are lacking in regional and remote areas, then it is critical that access to city based services be facilitated for those requiring care and treatment.

As our research into the [8]NSW scheme demonstrated, there are major inadequacies with the Scheme which only partially offset the real travel and accommodation costs of families who are travelling from regional and remote areas to the city. Subsidies do not meet the real expenditures (food, travel, accommodation, loss of employment) incurred by many families who as mentioned earlier, are already heavily and financially disadvantaged meeting the care costs involved with DMD/BMD.

The Save Our Sons Duchenne Foundation has also reviewed a couple of the other state travel concession schemes such as Patient Assisted Travel Schemes (PATS) in South Australia and Western Australia. Both schemes appear to share the inadequacies of their NSW counterpart. Noting that most South Australian families are typically required to travel to Melbourne as there are no neuromuscular clinics in Adelaide, the [9]PATS provides a meagre 16c per km car allowance which is well below current ATO rates for work based travel. The scheme only subsidises up $40 per person per night accommodation costs and food is not covered. Similarly, the [10]WA PATS provides a car allowance of 16 cents per kilometre only and up to $115 per night for accommodation per patient and accompanying family member. No food expenses are covered.

While some plane travel is covered by these schemes, transporting young men dependent on wheelchairs in planes is typically problematic, (poorly equipped country airports and regional carriers) and often more hassle than it is worth.

The Save Our Sons Duchenne Foundation believes there should be a harmonisation of patient travel schemes across the country and a major injection of funding to ensure all out of pocket expenses incurred by families are met. In an ideal world, we would argue that this should become a Federal Government responsibility or alternatively, a public policy area where more Federal and State collaboration should occur – to ensure all

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[8] SOSDF submission to the "NSW Upper House Inquiry into Health Outcomes and Access to Health and Hospital Systems in Rural, Regional and Remote NSW" Page 19-21.

[9] https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/services/regional+health+services/patient+assistance+transport+scheme/

[10] https://www.wacountry.health.wa.gov.au/Our-patients/Patient-Assisted-Travel-Scheme-PATS

health service users (including rare disease communities) have equitable access to high quality medical (including GP) and specialist services provided in the capital cities and major centres.

Finally, the necessity for such schemes, and the need for many families in regional and remote locations to travel for quality (and coordinated) care, is perhaps best summed in the following statement from a mother with a son with Duchenne:

> *" There are cross jurisdictional issues for those of us who live here and want to access the closest expertise (Sydney). Some of the families here go to Sydney, others to Melbourne – we don't have the necessary specialty expertise here. So for years, we've gone up and down the highway for appointments – very long days, physically and emotionally. I suspect it may be the same for others who live in border areas eg, Tweed and Albury. As my son transitions to adult care, we're again facing the difficult choice of whether to stay local and hope that the relevant specialties know or quickly learn something about DMD care (and can coordinate between themselves) or whether to go to Sydney (advantage of expertise, but more complex travel logistics and not ideal as the condition progresses and more interventions may be needed). There are clearly complications with sharing of patient records, funding allocations etc. At one level, I understand this. At another, it infuriates me that there are additional hurdles to ensuring that my son receives good care".*

Medicare Rebate Freeze: "*Hurting both the GP and the Patient*"

The Save Our Sons Duchenne Foundation will only comment briefly in relation to this matter which has been included in the Inquiry, Terms of Reference. As should be evident, keeping GP services as cheap and as accessible to our community as possible must be a priority, given the huge ongoing medical costs families are required to meet – and which are not met entirely by NDIS.

The Medicare rebate freeze has arguably pushed a number of medical costs onto families and/or limited the range of services a GP was able to offer. This is because GP rebates had been capped at 2014 levels for several years and despite increases in practitioner operating costs and overheads. In outer metropolitan, regional and rural settings where there are fewer GP and primary health service options (and less incentives to practice in these communities) it is subsequently essential that any rebate freeze be informed by the financial impacts on GPs and the communities they service - including families dealing with rare diseases.

The impact of the COVID -19 pandemic on doctor shortages in outer metropolitan, rural and regional Australia; *"Locked down and locked Out"*

For several of our families living in more remote and rural areas, it has been the border closures resulting from COVID 19 which have had the most impact on access to medical services. One family in northern NSW recalled the difficulties they have experienced accessing specialists and Doctors based in Brisbane during the period of the pandemic due to the border closures. Travel to Sydney has also not been possible for this family given the restrictions in place and the very real threats posed to the health of families by outbreaks of COVID. Subsequently, treatments have largely been foregone to the detriment of the young man who is struggling with the condition.

As with many other patient groups in the general populace, SOSDF has assumed that many boys and young men did not participate in the usual suite of therapies and medical appointments because of COVID lockdown and closures. As many of these boys and young men have heart and respiratory issues, it is probable that many families took higher precautions during the pandemic and were less inclined to spend time "out and about" and in potential exposure sites.

As our [11]NSW Inquiry research highlighted, telehealth played an important role for families who were not able to access direct GP and other primary health services during the pandemic. Be that as it may, telehealth was not viewed as the panacea nor as an adequate substitute, for a number of tests and scans and observations which are required and conducted in direct consultation with medical practitioners.

Conclusion

The contribution to this Inquiry by the Save our Sons Duchenne Foundation has been made in good faith and accurately reflects the feedback we have received from families who participated in our consultation process. The recommendations which follow will subsequently reflect the ideas and input we have received.

In summary, it is critical that our community members irrespective of postcode, have good access to GPs and primary health service professionals who can deliver services

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[11] Save our Sons Duchenne Foundation submission to the "NSW Upper House Inquiry into Health Outcomes and Access to Health and Hospital Systems in Rural, Regional and Remote NSW" Pages 17-19

which are informed and sensitive to the needs of people impacted by Duchenne and Becker muscular dystrophy. Unfortunately, this cannot always occur given the complexity of the condition and the competing array of rare diseases and other conditions which are vying for public attention (and funding priority).

More Government investment to ensure that current gaps in GP provision are met and/or alternative strategies in place such as those suggested by our families would be an important step towards alleviating the huge medical, social and financial burden experienced by those with lived experience of Duchenne and Becker muscular dystrophy

The Save Our Sons Duchenne Foundation and our broader community wishes the Committee well in progressing this Inquiry and we are more than prepared to contribute further should the Committee wish to communicate directly with us.

Finally, we conclude with a quote from a mother of a son with Duchenne in North Queensland. SOSDF believes this provides some great insights into the experiences of our community members as well as outlining some of the challenges which lay ahead for policy makers seeking to address GP and primary health gaps in outer metropolitan, regional and remote Australia:

"*The mismanagement of adults is so much more frequent outside of the capital city hospitals- and often care of adults is not as considerate as I mentioned above. We hear so many stories of medical mismanagement that many families would never consider to leave their adult with DMD alone in any hospital, let alone a rural one. The recent experience of being powerless, having no hospital advocate to speak with and not knowing how to access or navigate more help, feeling unwelcome and there not being enough disability equipment to help carers help people with disabilities wait less often when in pain or at risk of indignity are things we both want to improve.*

In the past couple of years we've lobbied for retaining allied health positions in rural areas and talked about also training them specifically for this type of service, or building the training facilities in the rural area so as to keep them local and also providing incentives. I learn from these long term rural people about things you and I wouldn't even think of – much like bureaucrats in the city. So I support them because they have the lived experience of true rural life like we had when living in Hughenden for a handful of years. It seems often that our rare disease concerns are not important given the general neglect in rural areas for all people".

However, rare disease is my experience and for others it is rare cancers so our experiences are reflective and in helping someone with cancer or with neuromuscular disease, most patients will be better off for the changes"

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Recommendations:

This list is by no means exhaustive and has been developed from the ideas discussed during the SODF community consultation:

1. That the Senate Standing Committee on Community Affairs, look to broaden opportunities to expand community consultation/engagement as part of this current Inquiry process.

2. That the Federal Government develop strategies to ensure that increased training and awareness of rare disease conditions such as Duchenne and Becker muscular dystrophy is provided to GP's and other health professionals both through University courses/training and ongoing professional development training packages. Further, that there be consultation with rare disease communities and patient organisations over the content and format of this training.

3. That the Federal Government sponsor efforts to develop more resources and materials for GPs and other health professionals working in outer metropolitan, regional and remote areas on Duchenne and Becker muscular dystrophy and other rare disease conditions – that this be done in consultation/partnership with organisations such as the Save Our Sons Duchenne Foundation and the community we represent;

4. That the Federal Government explore the possibility of establishing a national GP and specialist Duchenne and Becker telehealth service to provide 24/7 support to families and young people from the Duchenne and Becker community requiring medical advice and support – this being especially relevant to those

families and young people living in regional, rural and remote areas without immediate access to such support in their local area;

5. That the Federal Government explore, fund and promote "shared care" models and partnerships between GP's in regional and remote areas and rare diseases specialists (inclusive Duchenne and Becker) who are based in the capital cities and major population centres;

6. That the Federal Government provide more incentives and infrastructure to attract more GP's to outer metropolitan, regional, and remote locations -and target more GP's with rare disease experience and knowledge;

7. That the Federal Government identify current gaps in GP and primary health provision in outer metropolitan, regional and remote areas with a particular focus on rare diseases. For example, unlike WA, Victoria, NSW and Queensland there is no access to a state based neuromuscular clinic for families in South Australia.

8. That the Federal Government review State based travel assistance schemes for patients in regional and remote areas and play a more direct role in the coordination and enhancement/expansion of these schemes.

9. That the Federal Government organise to consult directly with rare disease communities such as the Duchenne and Becker muscular dystrophy community over the provision of GP and primary health services -especially given the limited timeframe for this Inquiry.

Bibliography

1. McKell Institute Report "*Living with Duchenne and Becker in Australia: Supporting Families Waiting for A Cure*".

2. Save our Sons Duchenne Foundation submission to the "NSW Upper House Inquiry into Health Outcomes and Access to Health and Hospital Systems in Rural, Regional and Remote NSW" November 2020.

3. SBS News 9 February 2019 www.sbs.com.au

4. ABC News 14 March 2019 www.abc.net.au

5. Australian Institute of Health and Welfare "Rural and Remote Health" 22 October 2019

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7. https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/services/regional+health+services/patient+assistance+transport+scheme/

8. https://www.wacountry.health.wa.gov.au/Our-patients/Patient-Assisted-Travel-Scheme-PATS

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ATTACHMENT ONE:

1) Save Our Sons Duchenne Foundation YouTube Documentary

This 8-minute video is available on YouTube and produced by Save our Sons Duchenne Foundation which gives a brief overview of Duchenne muscular dystrophy and the work of Save Our Sons in finding a cure to this condition.

https://www.youtube.com/watch?v=GcI7od9fqxs

2) 6 of 9 Documentary

The following 45-minute documentary was made as a lasting gift for his family by Martin Dix a Melbourne born and raised film maker residing in Los Angeles. It is the story of Martin's brother Kieran who suffered from Duchenne muscular dystrophy and passed away some years ago. When COVID 19 struck in the US, Martin finally found the opportunity to edit over 40 hours of archival footage of his brother Kieran's life – footage which had been left stored away for many years. What he finally produced is a moving documentary which documents both the lived experience of Duchenne for those who suffer directly from it, but also the huge emotional and personal impacts for those who care and love someone with the disease – in this case, Martin’s seven other brothers and his mum and dad. Save Our Sons Duchenne Foundation feels honoured that Martin wanted our organisation to use this film as part of our advocacy work and on that basis, we are privileged to be sharing this with members the Senate standing Committee of Community Affairs.

https://vimeo.com/427928501?fbclid=IwAR10sETVXNJLt7on1Og2FlDjo8GFKIbIB1ahyxuSrMbt_9y2-X9WIjxgR9s

ATTACHMENT TWO