



GSDV as it does not seem to occur in other metabolic myopathies and when objectively assessed is essentially pathognomonic for GSDV [5]. 'Second wind' generally begins approximately ~10min after the onset of activity despite no change in work rate. Pearson et al first observed and reported this occurrence and described it as a sudden improvement in exercise tolerance associated with a decrease in pain, heart rate and dyspnea [6]. Physiologically, the 'second wind' represents the lag that exists in supplying sufficient energy for working muscles as a result of deficient glycolytic (*i.e.*, 'fast') muscle metabolism and the time taken for the release of glucose from the liver glycogen stores-since the liver isoform of glycogen phosphorylase is not deficient in GSDV-and fatty acid oxidation (a slower metabolic pathway) to provide the required energy for working muscle fibers [4]. Some patients do not recognize the occurrence of 'second wind', however the occurrence thereof can be identified through objective monitoring (*i.e.*, decrease in previous tachycardia with the use of a heart rate monitor after ~10min constant-load cycle-ergometer exercise at moderate intensities [7].

Many primary care physicians, nurses, researchers and policy-makers remain largely unaware of this rare GSD, its presenting symptomatology/treatment, and the impact it has upon those affected. Current research literature highlights clinical features, manifestations of acute crises and varying treatment modalities; however, it fails to identify how GSDV impacts the day-to-day lives of those affected. Although GSDV affects a small number of individuals, it is worth noting that this cohort often becomes isolated and marginalized in healthcare systems that are more accustomed to dealing with common diseases. Limited access to specialized services, compounds the challenges around timely diagnosis and efficacious management, leaving the health of this patient cohort reliant upon conscientious self-management. The Highly Specialized McArdle Disease and Related Disorders Service in London, United Kingdom (UK) is the only known Centre of Expertise (CoE) that provides comprehensive diagnostic and ongoing disease management for a large cohort people with GSDV.

A patient-led online survey tool was developed that focused on Patient-Reported Outcomes (PROs) including: diagnosis, physical activity, nutrition, psychosocial aspects, pain, pregnancy and delivery, adverse events, access to care, and Health-Related Quality of Life (HRQoL). The aim of this cross-sectional patient-led international survey was to develop a holistic understanding of the day-to-day life of individuals living with GSDV, including HRQoL in order to inform future research and the continued development of health policies, such as the use of CoEs, for this condition.

## Methods

### Study design and participant selection

This study used a descriptive cross-sectional design and was made internationally available to individuals and parents of children with GSDV through the online survey platform Survey Monkey. The survey was available for a period of four weeks in 2016. The inclusion criteria included: 1) having received a

medical diagnosis of GSDV; 2) being able to understand English language; and 3) age  $\geq$  5 years. Individuals between 5–17 years were invited to involve their parents/guardians in answering the questions.

A purposive sampling approach was used, and the sampling frames included the social networking site Facebook–McArdle Disease group and the Association for Glycogen Storage Disease, UK (AGSD UK); both of which support individuals with GSDV. Institutional Review Board (IRB) approval was obtained through D'Youville University (USA). Voluntary participation in this online survey was accepted as consent.

### Development of the survey tool

As there is a distinct lack of research exploring PROs in GSDV, a survey tool was developed specifically for this study, which included a validated HRQoL questionnaire, the Short Form-36 Health Survey, version 2 (SF-36v2).

A thorough literature review of the clinical impact of GSDV, along with a comprehensive audit of previous unpublished patient surveys served to inform survey development. Through extensive consultation with a patient representative for the UK CoE and the patient advocacy group: Association for Glycogen Storage Disease UK (AGSD UK), a comprehensive first draft of questions was generated. The survey tool has five sections that endeavor to capture the day-to-day experience of individuals diagnosed with GSDV: (1) Measures of Functioning and Well-being (Diagnosis, Physical Activity; Nutrition; Psychosocial; Pain; Pregnancy and Childbirth; Adverse Events); (2) Access and Care for GSDV; (3) Overall Health and Well-Being (SF-36v2); (4) Demographics; and (5) General comments and advice for other patients. In total there were 65 questions (Supplementary Material). The tool was piloted with six people with GSDV for readability, clarity of instructions and ease of following questions. The Flesh-Kincaid grade level for the survey was determined to be 6.4.

### Statistical analysis

Descriptive statistics were predominantly used to characterize the data. Data from the SF-36v2 was analyzed with Quality Metric Health Outcomes Scoring Software 5.0. A four-week recall period was used with 2009 US general population norms. Mean t-scores were produced for the two primary measures, Physical and Mental Component Summary (MCS), and each of the eight health domains: Physical Function (PF), role limitations caused by Physical Problems, Bodily Pain (BP), and General Health (GH); MCS: Role limitations caused by Emotional Problems (RE), Vitality (VT), Social Functioning (SF), and Mental Health (MH). With norm based scoring, the average for each scale is 50 (Standard Deviation [SD]=10). The further a score falls below the norm of 50, the greater burden of illness there is. When considering group-level data, it is recommended that scores within 0.3 SD of the mean be considered within the 'average' or 'normal' range" [8]. Therefore, any health domain scale  $>53$  or below  $<47$  should be considered outside the normal range.

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Overall, n=168 (59%) of respondents were diagnosed by muscle biopsy, n=47 (16%) by DNA analysis, n=54 (18%) by both, and n=20 (8%) by other means (e.g., family history, elevated Creatine Kinase (CK), non-ischemic forearm test, EMG). Baseline CK levels-a routinely assessed marker of skeletal muscle damage-were self-reported by n=172 respondents. Twenty-two percent had a baseline CK (measured in a diagnostic outpatient setting)



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Table 4: The study investigated the following: (1) pain; (2) exhaustion; (3) interference with daily activity; and (4) depression. To help manage emotional concerns women tended to seek out/want support more frequently than men ( $X^2(4)=23.46, p < 0.001$ ). Cramer's V results showed a moderate association between gender and support for emotional concerns ( $V=0.292, p < 0.001$ ).

Emotional and psychosocial: Respondents were asked how GSDV impacts them emotionally; what their primary management concerns were; how satisfied they were with their ability to do what they wanted to; and whether they received support for emotional concerns related to having GSDV. More than half of the respondents reported an emotional impact related to living with GSDV. One hundred and sixty-five (57%) respondents often felt dissatisfied with their physical ability to do what they wanted to as a consequence of having GSDV;  $n=171$  (59%) were often embarrassed about having to stop and rest during activity because of GSDV; and  $n=189$  (65%) felt that others did not understand how they were feeling.

Results indicated that the majority of respondents (65%) felt that others did not understand how they were feeling. The study also found a moderate association between gender and support for emotional concerns ( $V=0.292, p < 0.001$ ).

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Table 5: Sensation(s) felt within the first minutes of activity after having pushed too hard.

When asked how much GSDV related muscle pain interfered with various daily activities over the past four weeks, respondents indicated two activities that were moderately to extremely impacted; 63% indicated their ability to walk and move about was affected, and 70% indicated participation in recreational activities was affected.

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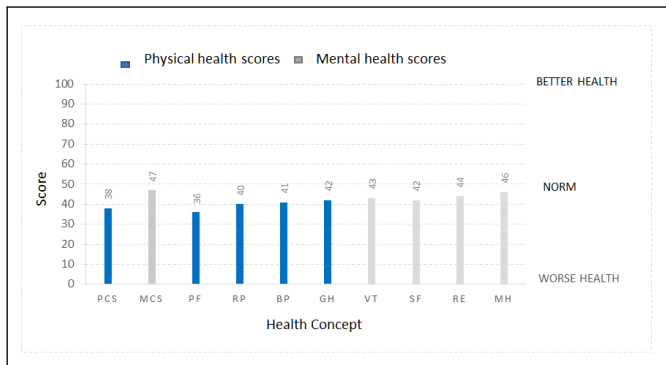
Eighty-seven (30%) respondents identified they live in the UK, and of those, 60 (21%) indicated they attended the UK CoE. In Canada, 4 of 15 respondents (27%) were seen by a GSDV specialist (defined in the survey as a medical doctor that has specialized education and training related to GSDV, and actively provides care to GSDV patients); in the US, 9 of 153 respondents (7%) did. Patients reported benefit from care by GSDV specialists

Nearly three quarters (n=210 [73%]) of respondents indicated they have received support from a community-based organization. Open-ended questions were analyzed, and three main responses emerged: (1) GSDV Facebook group (n=124 [59%]); (2) AGSD UK (n=55 [26%]); and (3) Muscular Dystrophy Association (MDA) (n=22 [11%]). Of note, the International association for muscle Glycogen Disorders (IamGSD) was established in 2017.

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Abbreviations: PCS-Physical Component Summary; MCS-Mental Component Summary; PF-Physical Function; RP-Physical Role Functioning; BP-Bodily Pain; GH-General Health; VT-Vitality; SF-Social role Functioning; RE-Emotional Role Functioning; MH-Mental Health.

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6WD\ DFWLYH	H[HUFLVH GDLO\ NHHS HYHU\GD\	DFLW\Y ZHDONZVRUNRQFRXUDJH \F GDLO\ ,I \RX GRQ W NHHS P ZRUVH \$V KDUG DV LW LV N
0DLQWDLQ D KHDOWK\ ZHL	DKWLG ZHLJKW JDLQ ZDW	FKR\RXWZHHJKWR YHUZHHLJKW LGHDO ZHLJKW /RVH ZHL RYHUZHHLJKW
+DYH D JRRG DWWLWXGH	OLYH \RXU OLIH GRQ W FRQGLWLRQ	JLKRK KSO DFLPHSW IRQO OLIH VPOO VWXII %H NLQG WR HDV\ *HW RQ ZLWK OLIH < DQG DPD]LQJ OLIH
<RX DUH QRW DORQH	\RXU\UH QRW DORQH WDON	N\WVRVQRKWUMXVW \RX WKHUH WKHUH <RX UH QRW DORQH QRW FUD]\
Q ZLWK GDWD		

d o V V v s A ] ( } CE v A o C % ] Y P w s - X A ] s Z } μ s u μ • o ] } % • C X ^ } u CE • % } v v s •  
u μ • o ] } % • C o } v U v u } CE o CE u ] v P o C  
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/v • ] P Z s ] v s % Z v s A E % CE ] v ] • ] u % CE s v X ( } CE ] • μ • μ o o C Z ] P Z CE s Z v i i i i  
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• s μ C CE • s Z μ CE CE v s P % ] v ] v } X o CE u % } Y A ] P v } • } ( ' ^ s % CE Y • s % v s  
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} u u } v ] • • μ • s Z ] • } Z } CE s ( • } v CE v ] v P } ] P v } • } U % } Z C } o } % v s • X  
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CE v s o C CE % } CE s μ CE } % } v } Z } CE s • } o f o v Y A ] d Z v P u % } CE ] μ o s } P d ] v CE % } s  
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} v • ] CE Y } v Z } A ] u % } CE s v s CE o C % } Y P v } • } • } • } • } CE ] s Z ] v } s Z ] v } s Z ] v }  
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Y A ] s v C } o CE v CE Y u • C CE } v } } CE X A ] v [ U v • CE A • v ] u % } CE s v s • CE v ]  
K μ CE • μ CE A C u } v • s CE % } Y s Z E s v } } s o p o ] P v } % } Y v s • X  
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μCE]vP šZ CE }À CEÇ %oZ • V šZ u CE Ÿ v v in (p r e f e r e n z e o f G S E V w i t h t h e i r d a i l y a c t i v i t i e s a n d c o n c e r n s  
 ]o]šÇX v ]u%o}CEš v š u%o• Ÿ P v š CE }CE] CE u o n d i n g d e p r e s s i o n .  
 Z }•%o]š o]CE Ÿ P v CE o • • } ( š Z CE • } v U ]• š } u v CE • š v Á Z š  
 ( š } CE • } v š CE ] μ š u ] o } v š Z U ] CE } o CE v • š CE š P ]• While clinical, objective data is of the utmost importance, the  
 š } Á ] ] ( μ š μ CE %o ]• } • X K ] Á CE v P v Ÿ v š Á } subjective experience adds a layer of understanding and  
 } μ š Z } Á š } Á ] ] š Z • Á + v š Ÿ Á - š Z CE } μ P Z authenticity that only those who have experienced the  
 u v P u v š • U š Z CE ]• v š } %o CE } Á ] phenomenon at hand can provide. The advice respondents  
 š } ] v ] Á ] μ o • CE P CE ] v P %o CE } u %o š dispensed was in large part, in accordance with main-stream  
 u v P u v š U v š } ] u %o CE š • š CE š P ] • ( } CE CE P ] v ] v P CE } recommendations; however, the more elusive lessons are worth  
 . š v • € í í • X observing-educate yourself; get support from family, friends,

d } CE • • P } P CE %o ] Z ] ( μ Z o ] Ÿ š Z P %o • e m b a r r a s s e d ; h a v e a g o o d a t t i t u d e ; a n d y o u a r e n o t a l o n e . N o t  
 ] v } Á o P U ] v ] Á ] v š μ CE v š } š Z ] v š CE v š o n l y d o t h e s e r e c o m m e n d a t i o n s c a p t u r e t h e f i r s t - h a n d  
 ] • • & } ] ] P CE } μ %o Á • š Z u } • š ( C E x p e r i e n c e s o f t h o s e e f f e c t e d } CE } they illuminate the benefits of  
 • } μ CE ] v } CE u Ÿ v • μ %o %o } CE š U Á ] š Z š Z h i n d s i g h t [ 2 7 ] • } v X  
 • u } CE %o Ÿ v š } μ P Z v } CE u Ÿ v o ] v U š Z v ( } CE v  
 ] v š CE v Ÿ v k u Á ] v š X • • μ Z U > ] u ] š Á š ] v v • ^ š CE v P š Z •  
 • š o ] • Z ~ í í ó • X d Z ] • W K • μ %o %o } CE š • ] v ] Á ] μ o • Á ] š Z u μ • o  
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š Z %o Ÿ Á š Á %o ] ] v š U ] • • %o ] CE š Ÿ v u š } v š CE ] μ š %o CE • v š u š } Á ( } CE • μ CE Á %o } ] %o P o š CE v CE  
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 } v Ÿ v μ + } CE š μ • š u š } CE ] • Á CE %o CE ] u CE Ç } v CE v • • } ] š Á ] š Z š Z ] • u š  
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 %o Z Ç • ] ] v • v } š } CE • X Ç ] v ] ] A P μ ] d • Á o o } CE ] v P š Z } • u Ç r š ] r Ç AE %o CE ] v U Á  
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 v Z v ] v P } v š v š } v ' ^ • ] v ( u ] o Ç v o u } CE P š ] Ç u } š ] v ' Á ] š Z • } ] o • ] CE ] o ] š Ç  
 CE • ] v Ç %o CE } P CE ] v P U Ÿ v μ ] W P ] o μ Ÿ v AE ] • š X • • μ u %o š Á ] v u š Z o š CE š ] ] CE • v %o v  
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d Z ( } CE u Ÿ } v / u ' ^ U v μ CE } %o } v h v ] %o š ] P CE W š Z } • ( CE u v } v r v P o ] • Z • %o ] v  
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 o ] v ] W CE Ÿ μ ] o ] v • ~ W ' • • ( } CE ' ^ s u v P u v š } • š Á • } š ] v ] v í í ó v  
 v } š Z CE ] u %o } CE š v š Á o } %o u v š Á € b i p • X Ÿ v • • } v P v š } v v š Z } • š Á • } š ] v ] v í í ó v  
 š Z , Z Y } %o } Ÿ v š } š Z ' ^ s ] • v ] u %o } CE š v š d Z ] μ o ] v o ] v v Ç ] • CE o š } š } š Z %o CE ] } C  
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 %o CE Ÿ v o } • š r + Ÿ u Á • μ CE ] v %o CE v ] Ÿ o Z U Z } μ v š } v š Z v š CE v Ÿ v } K o u ' ^ U v ( } CE %o }  
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K Á CE o o U u v ^ & r i ó %o } CE • Á } CE š Z ] Á CE } ] v CE %o } CE š X  
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 ' ] Á v š Z ] v Z CE v š ( š μ CE • } ( š Z ] • u š } v ] o u μ • } ] v Z Ç U o } Á  
 W ^ • } CE ] • v } š • μ CE %o CE ] • ] v P X d Z Ÿ Á Z š o d u CE ] • Ç u %o š } u } ( )  
 AE CE ] v } š } o CE CE G ] • š ] v o } Á W & • } CE u } μ μ CE • ] v } Á o P U š Z ] • %o } š š Z š • r o CE Á P Ç • š }  
 %o CE Á } μ • o Ç ] • μ • • U u μ • } b v CE o } š Ç u μ v ] Á ] • μ o • Á ] š Z ' ^ s AE %o o } CE ] v P } š Z š Z  
 Á ] š Z %o CE v š CE Ÿ } Ÿ B CE U • μ o } v P o } Á W • v AE %o ( CE v U v , Z Y } > X d Z ] • • š μ Ç %o  
 š Z ] • P CE } μ %o • Á u o μ X Ÿ v Z ( Ÿ Á ] š Ç ] AE CE CE ] %o š } š Z μ v ] ( μ AE %o CE ] v ( ( } š ] v Ç ] Á ]  
 ] v š } o CE v v u μ • o %o ] v o ] ] o Ç } v š CE ] μ š • € í ó } o š Z Á %o CE } u } CE Ç X ( } μ • • } CE š Z ] v } Á š

o š Z } μ P Z š Z D ^ • } CE ] • Á ] š Z ] v v } v š μ CE u š Z ] • u š Z } o } CE Á • š } ] v ( } CE u  
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 v } CE u o CE v P X d Z • • } CE • CE } v P CE μ v š } Á ] š Z %o CE Á ] ] μ o } CE Ÿ U v Á Z š Z CE  
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 ( o ] v P • } ( u CE CE • • u v š U v o ] } ( u v %o o ] • š Z v } v P } ( CE Ÿ U o } CE v U o ] v ] š } v CE  
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