

My muscles and me!

How my invisible difference affects me, and
...how you can help.

It is called McArdle's.
It is ridiculously rare, it affects only about
1 person in every 100,000.

- I got it from mom and dad, in the same way that I got my eye color and my height.
- The good news is that nobody can catch it from me.



- While McArdle's is invisible, the effect becomes very obvious.
- When I start activity my muscles quickly run out of energy – sooner than for other people.
- I may have to slow down, or pause for a rest.
- I must be very careful until my muscles build up energy again.
- If I do too much too quickly, I might become unwell and need medical help.



International Association for
Muscle Glycogen Storage Disease

How it affects me

- Unlike everyone else, my muscles cannot use the energy stored in them.
- When I start activities I run out of energy within a minute or two, then pain and cramping start.
- Demanding activity like running, lifting heavy things or opening a new jam jar, can cause the pain and cramping to start after just seconds.
- Stairs can be a real challenge, I go slowly.
- Sometimes it can really hurt.
- I have to be very careful and may need to slow my pace or pause for a rest and restart.
- After about 10 minutes I have a bit more energy and things get a little easier. We call this our “second-wind”.
- Sometimes, later on, I may feel even better and you might get the idea my McArdle’s is cured!
- But I can have problems again in a flash.
- ...and sometimes, I can’t do today what I could do yesterday!



I try to look after myself

- I allow plenty of time for tasks and activities.
- I take much longer than other people when walking up stairs or uphill.
- I take care to warm up and get into my “second-wind”.
- I usually rest for a minute before doing something risky, such as crossing a road.
- I try never to overdo things.



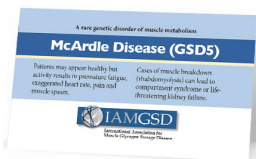
How you can help me

- When we are walking together I may need to slow down or even pause for a rest.
- Please don't tell me to hurry. It would be great if you can stay with me, but carry on if you need to.
- It usually takes only a minute or so for me to get going again.
- If I am carrying a heavy bag or a set of books, please don't be shy to offer to carry them.
- If you see me go to move, lift or carry something heavy – please remind me to ask for help.
- My problems can make me frustrated, embarrassed or sad. Your kindness and understanding will help me with these feelings.



If I get things badly wrong

- If I push on too hard or for too long, or something unexpected happens such as needing to move very quickly in an emergency, I can hurt myself badly.
- Some of my muscles may become swollen, sore and painful. I may start feeling very unwell.
- Please find an adult to help and take me to the hospital.
- Show the hospital my emergency card, so they know how to help me.



Can I help you?

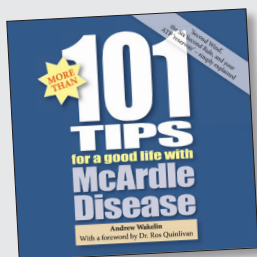
Please let me know if there is any way I can help YOU in return.



Want to know more?

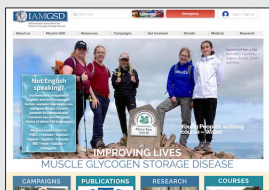
I would be happy to have a chat about my McArdle's. Just let me know that you would like to.

You might also like to have a look through my little book of



“101 Tips”, to get more of an idea of how I manage to live with my McArdle's. Please ask me to lend it to you.

There is also a lot more information on the IamGSD website under:
Muscle GSD, GSD5 – McArdle.
www.iamgsd.org



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Email: info@iamgsd.org

Web: www.iamgsd.org