



National Institute for  
Health Research

# Maximising Social Media

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Genetic Alliance UK

# Social Media



Getting the best out of your channels



**What we'll  
cover:**

- Social media platforms available
- Defining your target audience
- Creating your message
- Creating dynamic content
- Extending your reach
- Measuring you success

# Available Channels



Support  
Conversation  
Privacy

Mostly visiting on mobile  
53% female / 47% male  
Even demographic split  
Paid for advertising  
Issues around ownership/snooping



Visual  
storytelling  
Personalising  
Fun

14 million users in the UK  
59% 18-29  
Hashtags and locations are key  
Based on popularity of posts (70%  
don't get seen!)

No allowance of links – brand  
awareness only

# Available channels



Connecting  
Speaking  
Listening

80% mobile  
13 million twitter users in UK – 45%  
of all online adults  
37% login daily  
57% 30-49  
85% of tweets produced by 20% of  
accounts



Engaging  
Supporting  
Sharing

1/3 of all internet users use YouTube  
62% male 38% female  
44 and under make up 60% of users  
500 hours of video uploaded every  
minute  
Additional upload to Facebook

# Others to consider

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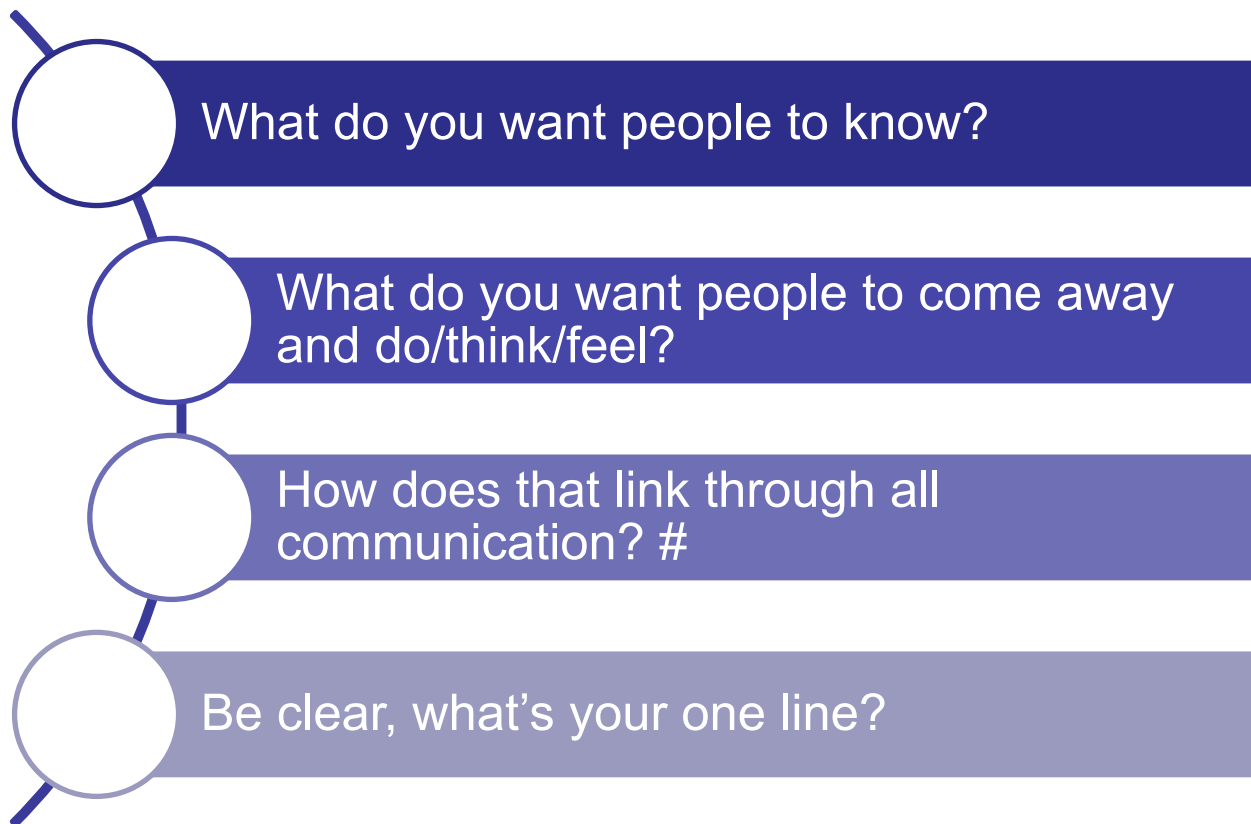


19 million  
users in the  
UK and  
growing

# Who are you trying to talk to?



# Defining your message



# Rare Disease Day 2018

**3.5 million people in the UK will be affected by a rare disease at some point in their lives - that's 1 in 17!**

**#1in17**  
**#RareDiseaseDay**

**RARE DISEASE DAY**  
28 FEBRUARY 2018

1 in 17 people in the UK will be affected by a rare disease at some point in their lives

**#1in17**  
**#RareDiseaseDay**

Hear hoofbeats?  
Think zebras.  
Think rare diseases.

For patient stories, info and 'Spot the rare', follow us:

- [rare-disease-day.uk](#)
- [RareDiseaseUK](#)
- [@rare-disease-uk](#)
- [rare-disease-uk](#)

Rare Disease UK is a campaign run by the charity Genetic Alliance UK. Registered charity numbers: 1114192 and SC036259.



**Spot the rare**  
**#RareDiseaseDay #1in17**

YouTube DE Search

**1 in 17 people in the UK will be affected by a rare disease at some point in their lives.**

3:22 / 4:15

# Creating dynamic content



- Gifs
- Infographics
- Videos
- Graphics
- Boomerang

This GIFF was produced by Rare Disease UK for Rare Disease Day 2018 – available to view at:

<http://bit.ly/2DGUmuG>



# Creating a conversation

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# Extending your reach



User generated content

Conversational content

Join the conversation

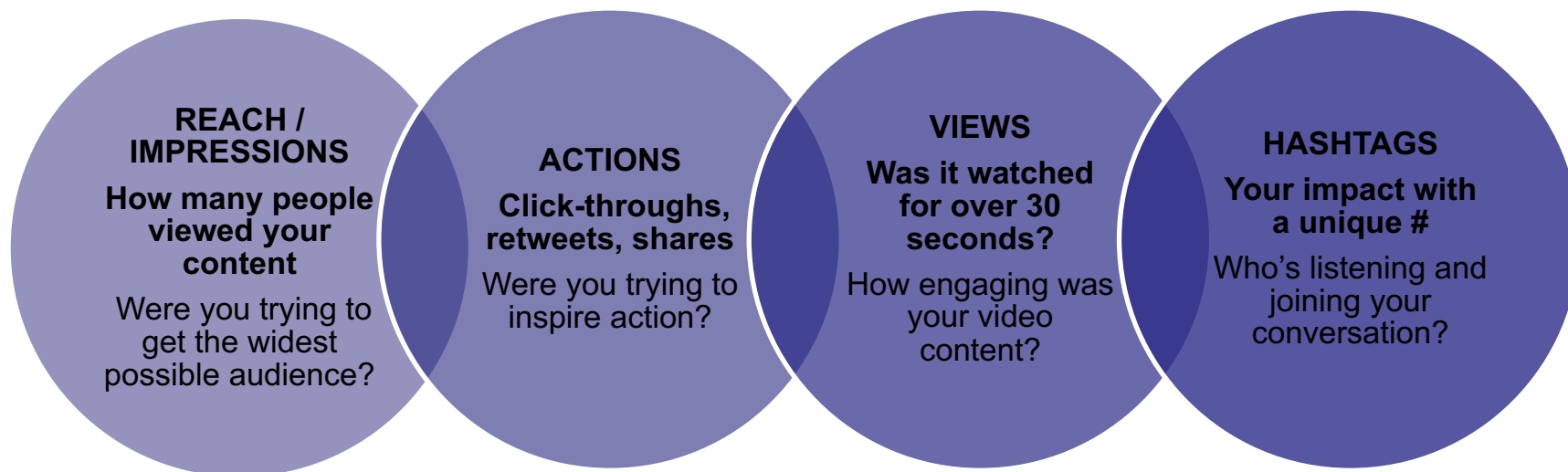
Shareable content

Identify key influencers

# Measuring success

*“I have been struck again and again by how important measurement is to improving the human condition.”*

Bill Gates





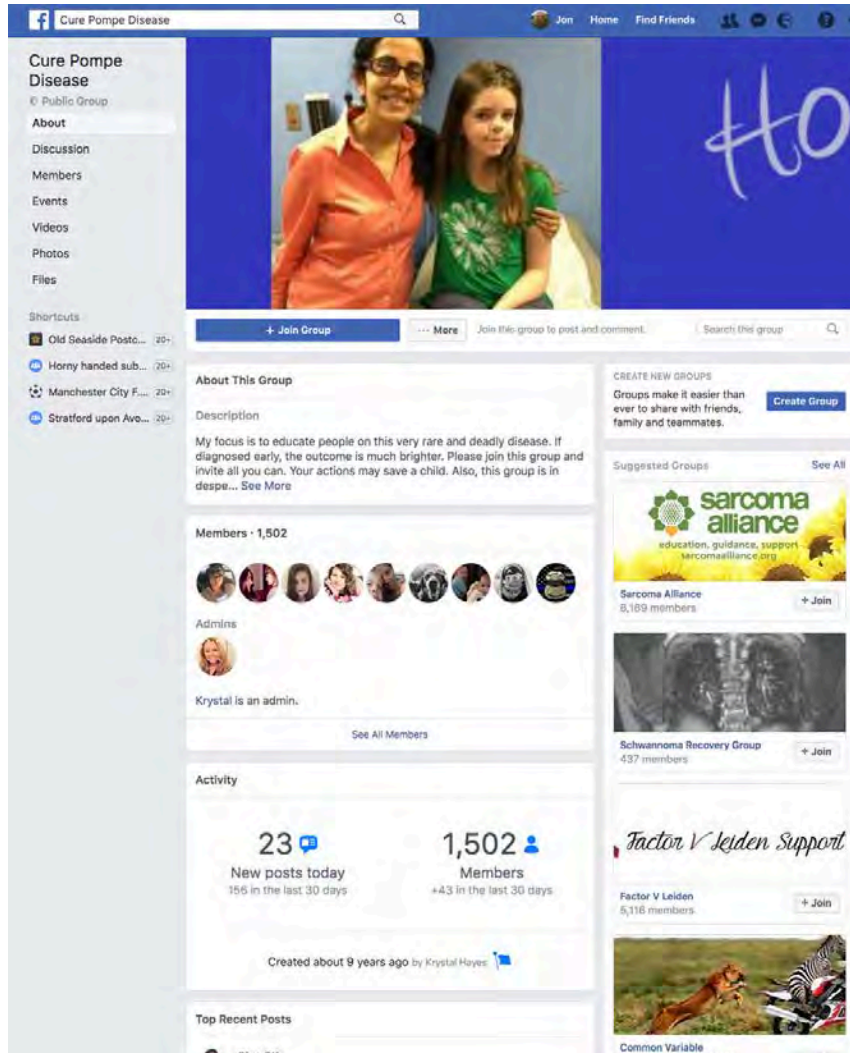
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# A patient's perspective on using Social Media

Gemma Seyfang

Pompe Disease Patient

# Social Media Groups



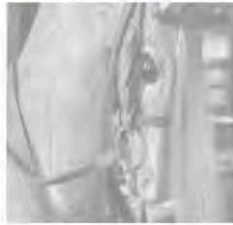


## Meet Pompe Patient Gemma

RARE as rocking horses that's what we are,  
Join me as I explain a snippet of my life so far.

The difficulty I feel to rise from certain chairs,  
And the way I struggle to climb up the stairs,

Often passers by presume that I'm drunk,  
Cos when I walk my hips sway to the front,



It's very easy for me to trip, stumble and fall,  
And if you're with me this may make you feel uncomfortable,

I've been told there are only 42 people in the UK,  
Whom are being treated for this disease by the NHS today,

The treatment that I'm receiving is aiming to keep,  
My muscles in a stable condition so I can stay on my feet,

My every day struggles include tying up my laces,  
Picking up something off the floor and reaching to high places,

Exercise is difficult even to walk for just a while,  
Will make my muscles hurt and ache even tho it was just a mile,

Climbing in and out the car or rising off the loo,  
Don't get me started on shaving my legs, it's difficult, it's true,

My Lung muscles are also weak, especially at night,  
It leaves me feeling unrefreshed when I wake with the morning light,

My family and close friends are always there for me,  
I cannot thank them enough and I love them, I hope this they can see,

This is my life, this is who I am,  
I will remain as independent as I can,

This disease is part of me and so I must embrace it,  
Become more knowledgeable, do all I can, so I can better face it,

Pompe Disease will continue to make my body suffer,  
But "Together We Are Stronger" is the motto that we mutter

I am like a diamond that's precious and RARE,  
I'm not like those stones that can be found everywhere

Please share to help raise awareness



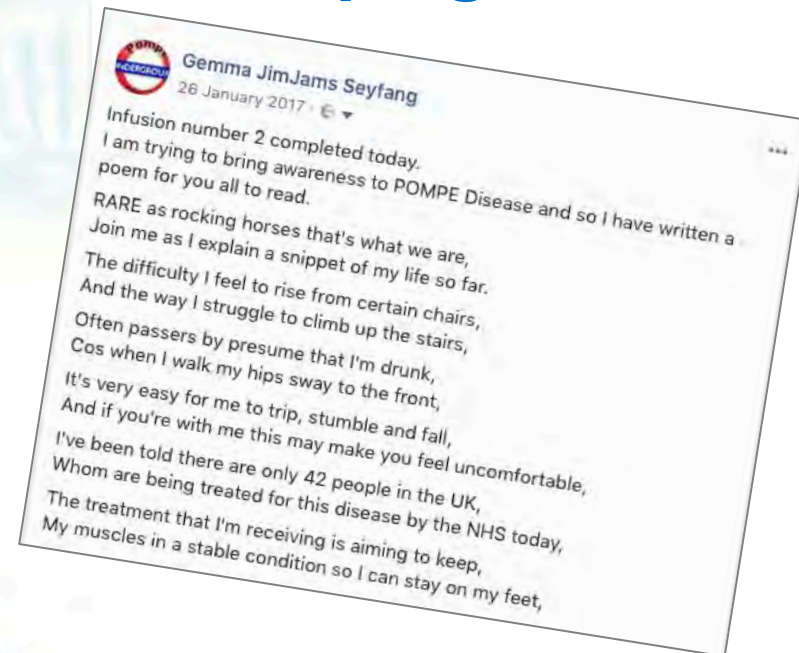
To find out more about Pompe Disease visit [www.pompe.com](http://www.pompe.com) and [www.agsd.org.uk](http://www.agsd.org.uk)



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# Poem

## The start of my social media campaign



# Response to my Poem

**Jo White** This is amazing.

What a talent. Definitely a brilliant way to raise awareness. Cheering you on.

And remember, diamonds are created because of the huge pressure and conditions exerted on them. A diamond represents stamina, endurance, strength and overcoming the most difficult circumstances to produce something beautiful and mesmerising that catches people's attention. No one will ever truly know the difficulties and struggles you face but they do see someone who radiates beauty, love and kindness. Someone who is strong and of good character and someone who values what they have, cherishes life and is loved by more people than you probably realise.

What an amazing lady you are. Xx

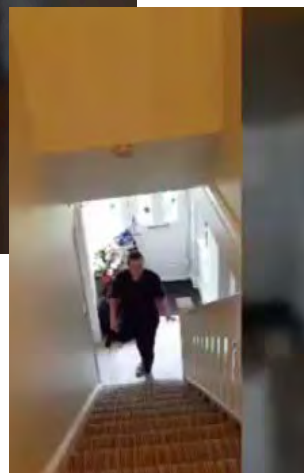
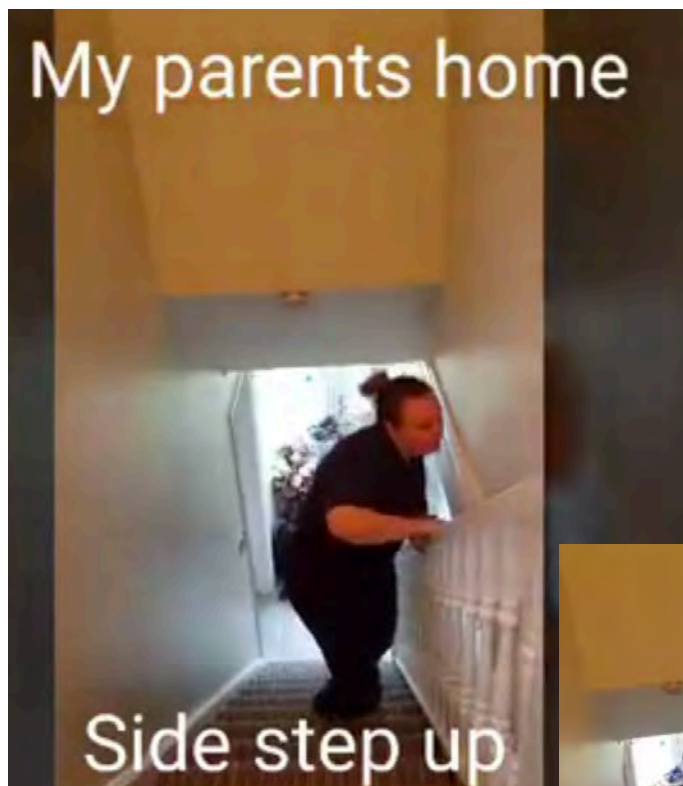
**Jules Golden** Awww **Gemma JimJams Seyfang** i loved reading that. I have to admit I've never heard of this condition before. Good for you for raising awareness. Stay strong my lovely 🥰 x 🥰

Like · Reply · 1y



**Gemma JimJams Seyfang** Wow thanks Jo. Interesting to read. I don't think I'm amazing at all but your words made me feel very happy so I thank you for that xx

# Climbing Stairs



 29 March 2017 · 👤  
 This is my inspirational friend who I worked with for a while.  
 She has made this video to raise awareness for POMPE a rare degenerative  
 condition that she has.  
 Great video Gemma JimJams Seyfang.  
 Cheering you on. Xx

Please copy the link to view this short video on how my condition affect everyday things, like climbing the stairs

<https://www.youtube.com/watch?v=Z1p-A9dfgjs>

# Positive News

2017 June



Gemma JimJams Seyfang

22 June 2017

POMPE AWARENESS 🙌

Today I had my 6 month physio check-up for the trial I am doing. This however, is no ordinary physio!!!!

Anyone that has been on a 3 year trial like this will know my pain 🙄

It was a bittersweet feeling though.

I completed my 6 minute walk test and my physio said, "Well done Gemma, your walking was so much smoother". I felt positive and upbeat.

I then smashed my next test!!!!

The stairs at the hospital are not "typical" stairs

They are what I call "school stairs".

The height of the step is probably just over half the size of the ones at our house.

But....a WIN is a WIN as my Pompe community say 🙌

I not only DIDN'T use the handrail,

But I also managed to get up without pushing my hands on my thighs.

I mean, it is only 4 steps they are testing me on, but as I said, a WIN is a WIN 🙌

I then had to sit on the floor and stand up as quick as I could using the least amount of help whilst being timed.

I looked like a penguin slipping on ice 🐧

Job done!!!

Then another progress....

I had to stand up from a chair (Sounds nice and simple) with the least amount of help.

I stood up by pushing off the arms of the chair (normal procedure).

I then said I would try pushing off my thighs (I would say I haven't been able to do this for about 2 years now) SUCCESS.

I then did it pushing up with one hand on a thigh

RESULT.

I then tried without any hands....I was stuck looking like I was bowing to my

2017 June

to do this for about 2 years now) SUCCESS.

I then did it pushing up with one hand on a thigh  
RESULT.

I then tried without any hands....I was stuck looking like I was bowing to my partner before starting a dance, or bending over to pick something of the floor!!!

But I took the positives...I had improved TWICE in this test ❤️

Next up.....into the Gym!!!

This was where I had to attempt to hop, kick a ball, jump a certain height, jump forward, walk backwards, walk on a line, run 🏃, squat, balance on one foot, pick something up off the floor etc etc  
All things I took for granted a few years back!!!

Then...the WORST part....

Strength/resistance tests.

My physio uses a handheld machine which has what can only be described as a muscle damage contraption on the end (evil).

He then pushes with all his strength against my arms, legs, hips, ankles, feet, wrists in different directions and I have to make a face like I'm in labour pushing a watermelon out and try to resist him from what he calls "winning". This takes at least an hour and by the end my whole body feels like I have been ran over.

And tonight, tomorrow and the day after I shall suffer from aches and pains because of these tests.

In fact I have sustained an injury from the first test 6 months ago, which was made worse 3 months ago from my second test and am now struggling to operate my right arm as normal 🙄

And finally....I'm done....until next time....3 months later when I can do it all again.

Yippeee!!!!!!

Finishing on a positive note 🙌

I smashed some results and definitely have more energy since starting treatment.

Whoop whoop ❤️

Please share to raise awareness.

# Devastating News



Gemma JimJams Seyfang Timeline 2017 June



Gemma JimJams Seyfang is 🥺 feeling heartbroken

24 June 2017

I have another medical condition that I have hidden for the past 5 years from most of the people that know me

It it's called Usher Syndrome (deaf-blindness)

I have an eye condition which is progressive

One day I may be completely blind

At the moment it mostly affects my vision at night

I cannot adjust to light changes very well

The easiest way to describe it is night blindness

Also I am losing my peripheral vision

Basically like tunnel vision

I also have been diagnosed with glaucoma which affects central vision and so I am taking eye drops 3 times a day to try to tackle this condition.

In March I received a letter from the DVLA

I filled in the health questionnaire and sent it back

I was then sent for an eye test

It has been 10 weeks since my test

I stupidly thought no news is good news

This morning a letter arrived

License revoked as of yesterday

I love driving

It is my independence

My freedom

I started driving aged 13 on private land

I took my first lesson on my 17th birthday

I passed first time 10 months later

Aged 17-20 I spent most weekends cruising with my friends

I have NEVER got into the car under the influence

I received 3 points when I was 18 as I was caught going from a 40 into a 30 at 34mph

I have only ever had a small bump that was my fault at 5mph where someone suddenly braked due to a person running out in front of their car

I cannot explain how devastated I am

My life will change forever

It feels so raw at the moment

I will get used to it

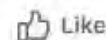
But I will never like it

There are some people on the roads that cause havoc

I am am safe driver

They should not be on the road

I'm so angry



Like



Comment



Share

# Going Out

So I went out for one of my closest friends birthday last Saturday evening  
We had a meal at a Chinese restaurant and then decided to hit a bar  
come nightclub in town

The thought of going out at night does make me quite nervous for a  
number of reasons and now that I'm having to be an actual grown up  
adult I don't get out as much as I used to....which means things are a little  
more scary.

So some of the things I tend to worry about (because they tend to  
happen) are as follows:-

Walking into things...like a chair or a table because I didn't see it

Walking into people because I didn't see them

Stumbling

Tripping

Falling over because I have done one of the above

Stairs without a handrail

Actually just stairs in general...or steps

Things that are slightly raised....such as a piece of the pavement or a  
drain or a mat in the doorway

Slopes and hills.....even the smallest

People that are drunk....because I can't see them to move out of their way

People that are drunk waving their drink around....because it normally  
ends up on me

Trying to talk to someone in the club...because I cannot actually see their  
face properly so when you lean across to talk to their ear I end up  
headbutting them or they have walked off already

Going to the public toilets because they are normally up or down a flight  
of stairs....the cubicles are tiny....I have NOTHING to pull myself up on and  
by now I am drunk so will not be able to push off my legs and so whilst  
trying to hang onto my bag (because there is no hook on the door and

there is no way I'm putting it on this floor even if I could bend down to  
pick it back up after) and trying to pull myself up on the toilet roll  
dispenser without pulling it off completely and by now I don't care if the  
toilet attendant thinks I'm having a fight with a donkey because I'm  
crashing and banging against the sides!!!!

People introducing themselves to me and then say "okay, don't shake my  
hand then!?" because I didn't even see their hand outstretched

People thinking I'm odd because about 3 different friends have held my  
hand at some point in the last 30 mins to guide me to places.....but I look  
NORMAL

The bouncer thinking I'm drunk because I'm wobbly on my feet even tho  
I've only had a couple of drinks and my sister telling the bouncer (in a  
drunken slurred voice because she has had double to what I've had)  
"She's not druuuuunk.....she can't seeeeeeeee, okaaaaaayyy"

Being laughed at by many people because I have fallen over.....and all  
they are thinking is "silly drunk girl"

My friends explaining that I can't see to some guys they are chatting to  
and them responding by saying "oh bless her" and then saying to me "my  
idea of a perfect date haha"

Getting into a taxi because I cannot get into a minibus unless I crawl in  
And I find it hard getting out of a low car

BUT most of all for being a burden to my friends or for embarrassing  
them

And after all of that (which is only a snippet cos in reality for me there are  
so many other things I find difficult or a problem) I REFUSE to allow my  
Disabilities to stop me from having FUN

So last Saturday I went out

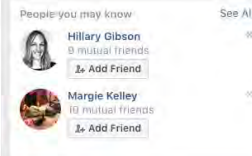
I danced a little

I joined in

So I hope I have inspired others to face your fears and get out there and  
enjoy your life because you only get one, and yes mine may be full of  
challenges, but I will not let it define me

Please SHARE to RAISE AWARENESS

Thank-you ❤️



# Smashed it again!



Gemma JimJams Seyfang Timeline 2017 September



Gemma JimJams Seyfang

18 September 2017 · 🌐

Smashed it 😊  
9 month tests for the COMET trial Myozyme vs NeoGAA  
Lung function and physio tests today  
Improvements again 🥳  
So frigging happy  
Pompe Strong 💪



Like



Comment

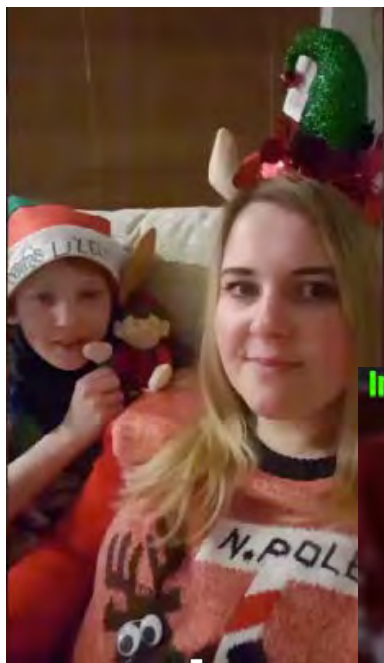


Share

# Christmas Jingle

Please copy the link below to watch our Pompe Disease Christmas Jingle

<https://www.youtube.com/watch?v=OfDXE7P1JKE>



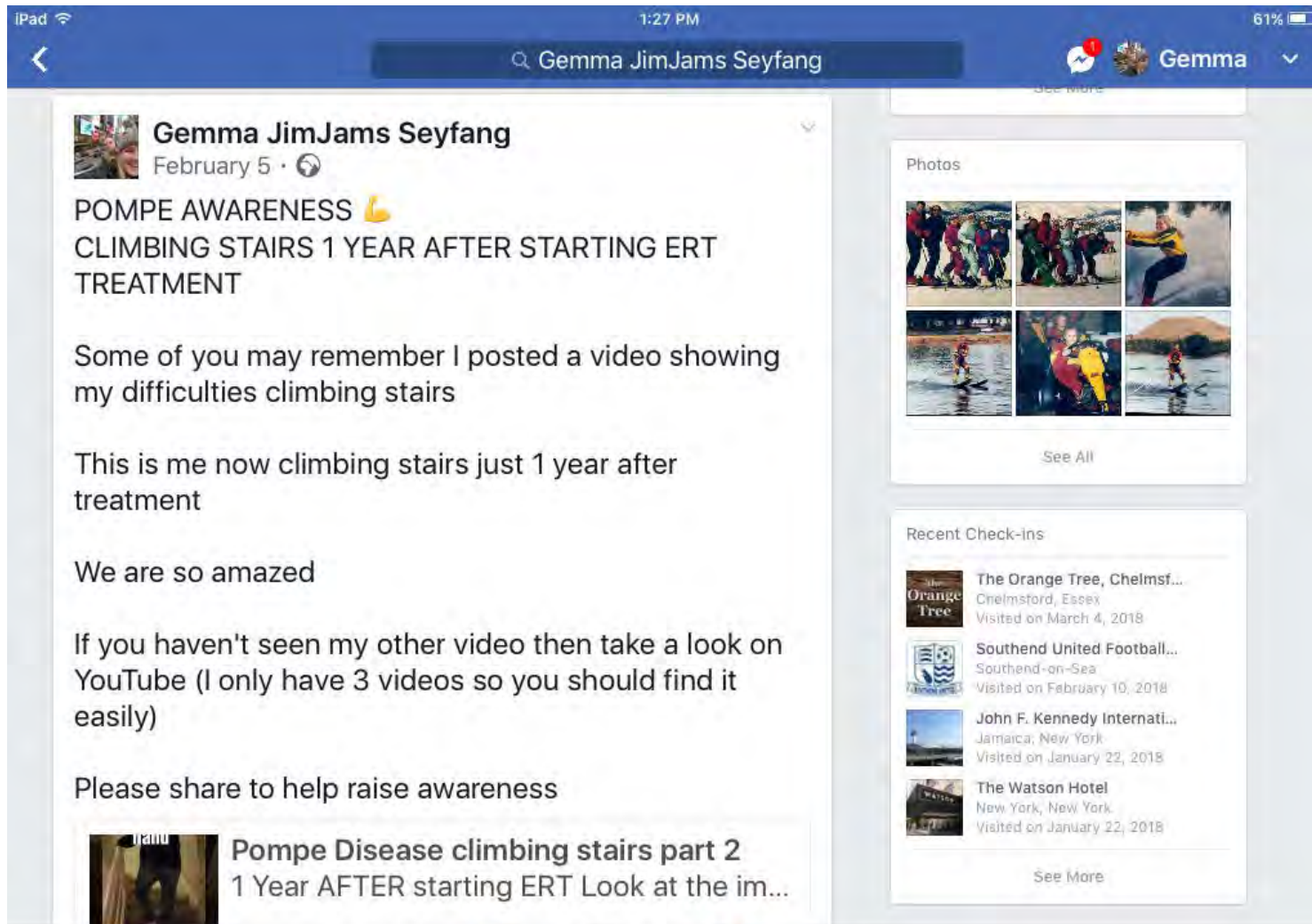
WOW  
In just under 24 hours we have had 1 thousand 500 views  
That's amazing  
We have also raised £84, through which 8 of you lovely people have donated  
If you can spare £2 please see how easily you can text to donate below...  
[See more](#)



**Gemma JimJams Seyfang**  
3 December 2017 · JustGiving ·

We are very excited to introduce our Pompe Disease Christmas Jingle  
Please SHARE our video to help raise awareness  
We are also raising money for AGSD a charity who helps support those with Pompe Disease  
If you wish to show your support and want to donate please text POMP66 £2 to 70070  
If you are feeling generous you can change the money to £3, £4, £5 or £10  
Thankyou to all those who took part in my crazy idea 😊  
<https://www.justgiving.com/fundraisi.../pompe-christmas-jingle>

# Climbing the Stairs 1 year on



# Learning



## 1. Give it a go!

*I had zero experience but was amazed by the reaction and support I was shown.*

## 2. Public profile

*Either make a public profile or manage who your audience are.*

## 3. Be honest

*The good and the bad bits.*

# Thank you



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*Questions? Comments?  
Time to share your own experiences!*