Teaching Course 14

Using social-media to manage and research MS

Chairs: A. Thomson (London, GB)
        D. Baker (London, GB)

38 What is social-media and how to use it?
    A. Thomson (London, GB)

39 How to use social-media to manage and research multiple sclerosis?
    D. Baker (London, GB)

40 How patients use social-media?
    J. Stachowiak (Santa Fe, US)
Teaching Course 14: Using social-media to manage and research MS

COURSE MANUSCRIPT
ECTRIMS 2015

COURSE INFORMATION:
DATE: Wednesday 7th October 2015
TIME: 12.30-14.00
ROOM: Hall G
LECTURE 1: What is social-media and how to use it?
SPEAKER: Alison Thomson, Queen Mary, University of London, UK
TWITTER NAME: @somehow_related

The following topics will be covered:

- What is Twitter and why has it become the phenomenon it has (#MSresearch)
- Harnessing the ability of ‘immediate’ communication
- Ground rules; the major do’s and don’t about creating a profile as a clinician or a researcher
- How it works – covering the basics and more advanced feature
- Professional etiquette on Twitter
- Who to follow in MS and Neurology (see Directory at end of manuscript)
- Establishing and keeping followers
- Essential third party tools and applications

LEARNING OUTCOMES

Upon completion of this course you will have set up a Twitter account with an appropriate homepage image, headshot and description. You will know different ways to build your network on Twitter and understand how to communicate with your followers. You will understand how lists work, how to shorten your tweets and how to delete and block tweets.
LECTURE 2: How to use social-media to research MS?
SPEAKER: Professor David Baker, Queen Mary, University of London, UK
TWITTER NAME: @prof_mouse

The following topics will be covered:

• How to define and tweak research strategy using social media
• Using social media to provide supportive data for grant applications
• Using social media to educate people with MS about the scientific process
• To define how to refer to people with MS in publications
• Using Google trends as a tool to interrogate online research fads
• Using social media to design a clinical trial
• Using social to crowd fund research

LEARNING OUTCOMES
Upon completion of this lecture you will know how to use social media to communicate with wider community to help you to research MS.

www.ms-res.org

www.clinicspeak.com/lumbar-puncture/
LECTURE 3: How to use social-media to manage MS?
SPEAKER: Professor Gavin Giovannoni, Queen Mary, University of London, UK
TWITTER NAME: @gavingiovannoni

The following topics will be covered:

- Social media beyond Twitter as an immediate, asynchronous, communication tool that allows you to communicate with a large number of patients in real time
- Using case studies to illustrate how to self-manage multiple sclerosis; for example bladder dysfunction.
- Empowering patients with knowledge and encouraging them to ask important and relevant questions in relation to the management of their disease; for example ‘what questions to ask your neurologist?’
- Tagging different posts to target different audiences and using these tags to select posts of interest, for example using IFTTT (if then then that, www.IFTTT.com)
- Using social media as a global education platform; blurring of boundaries between neurologists, other healthcare professionals and patients with multiple sclerosis; for example PML risk stratification.
- Using social media to counteract anti-science movements and ‘fads’, for example CCSVI and stem cell therapies
- Using social media to establish treatment protocols, for example strategies to switch high-risk patients from natalizumab to alemtuzumab
- Using social media to change clinical practice, for example encouraging the adoption of treating-2-target of no evident disease activity (NEDA)

LEARNING OUTCOMES

Upon completion of this lecture you will know how to use social media to communicate with patients and how to use web tools to target messages to specific groups of people. Specific examples will be used to show how social media can be used to manage MS.

www.clinicspeak.com
LECTURE 4: How patients use social-media?
SPEAKER: Julie Stachowiak

The following topics will be covered:

CASE STUDIES: Most frequent types of people/queries/comments (with short examples for each one):
  • “I thought I was the only one that X!”
  • “Symptom X feels like… Does anyone else feel this way?”
  • “No one understands my X.”
  • “For me, X works for Y symptom.”
  • “My neuro is great/horrible, because…”
  • “I’m considering X medication. Has anyone else tried it?”

CONCLUSIONS:
  • Most frequent comments and queries indicate that they don’t always feel listened to or understood by their neurologists or loved ones.
  • Patients with MS WILL use the Internet and social media, often to validate opinions that differ from clinical opinions.
  • However, (in my experience) there are not huge gaps between recommended courses of treatment and what patients want to do. What they really want is to be heard – prefer an “I don’t know” or “maybe” to a dismissal because the medical literature doesn’t cover the symptom.
  • Neurologists need to move past the trauma of CCSVI. Again, most patients just want their symptoms acknowledged and will rarely seek radical treatment.
REFERENCES: HOW TO USE SOCIAL MEDIA TO MANAGE MS?


REFERENCES: MS AND SOCIAL MEDIA

The following is a list of select references of research on multiple sclerosis and the Internet or social media, including topics on online research, health-seeking behavior and/or treatment:


TWITTER DIRECTORY:

Neurology Conference Twitter accounts:

@ACTRIMS
ACTRIMS, The Americas Committee for Treatment and Research in Multiple Sclerosis, was founded in 1995 to serve as the US and Canadian counterpart.

@ECTRIMS
ECTRIMS is an independent representative European-wide organisation devoted to multiple sclerosis (MS).

@theABN_Info
Offers information for consultant neurologists, trainee neurologists and their patients in the United Kingdom.

MS Charity, Fundraising events & patient groups Twitter accounts:

@mssociety
Multiple sclerosis stops people from moving. We exist to make sure it doesn’t.

@mssocietyuk
The UK’s largest charity for people affected by MS.

@MSTrust
We are here to support people with multiple sclerosis, their friends and families.

@SVIClub
Mission: be a leader in finding a cure and enabling people affected by MS to enhance quality of life

@WorldMSDay
Bringing the world together to campaign with & for everyone affected by multiple sclerosis. An initiative of MS International Federation & its network

@MSIntFederation
The MS International Federation is a unique global network of MS organisations.

@AsianswithMS
National Board of Asians with Multiple Sclerosis. Raising awareness and supporting MS’ers

@UKMSRegister
The UK MS Register is an innovative project to capture peoples experiences of living with MS in the UK.

Neurology Journal & Magazine Twitter accounts:

@nature
International weekly journal of science. Editorials, News & Views, corrections and primary research coverage here

@NatureMedicine
Nature Medicine is a biomedical research journal devoted to publishing the latest advances in biomedical research for scientists and physicians.

@TheLancet
Welcome to The Lancet on Twitter. Keep in touch with The Lancet, one of the world’s leading general medical journals, published weekly since 1823.

@NEJM
The New England Journal of Medicine (http://NEJM.org) is the world’s leading medical journal and website.

@NeurologyNow
Your trusted resource for brain health. Neurology Now magazine is a free public service of the American Academy of Neurology.

@NeurologyToday
Neurology Today is the official newspaper of the American Academy of Neurology, published by Wolters Kluwer Health/Lippincott Williams & Wilkins.

@neuroscience
Neuroscience | Latest news, research, books and journal articles in neuroscience, neurology, psychology and alzheimer’s disease. …

@sciencemagazine
The world’s leading outlet for scientific news, commentary, and cutting-edge research. Follow @NewsfromScience for our latest news.

@PLOS
PLOS accelerates progress in science and medicine by leading a transformation in research communication.

@NatRevNeurosci
Nature Reviews Neuroscience features reviews, perspective articles and the latest research news. Tweets are from the editors.

@NeurologyCP
Neurology® Clinical Practice is an official publication of the American Academy of Neurology.

@NEJM
The New England Journal of Medicine (http://NEJM.org) is the world’s leading medical journal and website.

@newscientist
The best place to find out what’s new in science – and why it matters.

Medical Institutional & Societies Twitter accounts:

@ABNTtrainees
Twitter feed of the ABNT - please follow for neurology trainee news

@bmj_latest
The BMJ aims to lead the debate on health, and to engage doctors, researchers and health professionals to improve outcomes for patients.

@StudentBMJ
For medical students and junior doctors, from the British Medical Journal

@BartsMSblog
Explaining the Good, Bad and Other MS Research News

@SocSocMed
Advancing knowledge for population health http://socsocmed.org.uk/join/

@RCPLondon
Representing 30,000 physicians, we set standards of medical practice, provide education/training, advise on healthcare & home to award winning@RCPmuseum.
**Figures in the field Twitter accounts:**

@XMontalban  
Neurologist, Cemcat, H. Vall d'Hebron (Barcelona), President of ECTRIMS

@bengoldacre  
NEW BOOK collected journalism OUT NOW http://goo.gl/5JUasQ  
Doctor, nerd cheerleader, Bad Science person, stats geek, procrastinator

@RFarrell_CNR  
Consultant Neurologist, UCLPartners Centre for Neurorehabilitation and Queen Square Centre for MS

@KlausSchmierer  
Neuroscience & MSology

@tim_coetzee  
Chief Advocacy, Services and Research Officer at the National MS Society

**Looking for some inspiration? Try these Twitter accounts:**

@TEDTalks  

@LegoAcademics  
The female academics of the Lego Research Institute take on the challenges of modern academia. CC-BY-NC-SA

@RunningMadProf  
Doctor, Researcher, Award-Winning Science Communicator. Director, Institute of Infection & Global Health, Univ Liverpool Walton Centre NHS…

@MARLODONATO  
Author of Awkward Bitch, My Life with MS. Fashionista, Musician, MS'er, Vlogger, Lover of life, wife of Tim Love, and proud mother of 2 beautiful children

@pintofscience  
A yearly science festival taking place in pubs in May - across the UK & globally. Get in touch and join us to communicate the latest science research!