Using social-media to manage and research MS

*social-media = social networking sites; for example Twitter, Facebook, Blogs, Wikipedia, Wikis, Pinterest, SnapChat, Google Plus, LinkedIn, SlideShare, etc.

Gavin Giovannoni

Disclosures

Professor Giovannoni has received personal compensation for participating on Advisory Boards in relation to clinical trial design, trial steering committees and data and safety monitoring committees from: Abbvie, Bayer-Schering Healthcare, Biogen-Idec, Canbex, Eisai, Elan, Fiveprime, Genzyme, Genentech, GSK, GW Pharma, Ironwood, Merck-Serono, Novartis, Pfizer, Roche, Sanofi-Aventis, Synthon BV, Teva, UCB Pharma and Vertex Pharmaceuticals.

Regarding www.ms-res.org survey results in this presentation: please note that no personal identifiers were collected as part of these surveys and that by completing the surveys participants consented for their anonymous data to be analysed and presented by Professor Giovannoni.
Why did I get involved in social media?

Time is my most precious resource?

Prof Giovannoni is working hard for you!

Overbooked, harassed
8 new & 20 follow-up slots per clinic
Double-bookings
Running between consulting rooms A & B
The 5-min history & 5-min neurological examination
<table>
<thead>
<tr>
<th>Time</th>
<th>Repetition</th>
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Why speak to the individual when you can have a dialogue with several Msers* at once?

Why repeat yourself?

*MSer = a neutral descriptor for someone with MS
A BLOG FOR PEOPLE WITH MS AND THEIR FAMILIES
“Interpreting the Good, Bad and other Research News”

WEDNESDAY, 30 JANUARY 2013

CCSVI treatment: no major effect

**Blog:** Venoplasty for CCSVI appears not to work. Do we need more data?

**Egges, O., et al.** The MS Study Group/Italian Society of Neurology.

**Background:** Although it is still debated whether chronic cerebrovascular venous insufficiency (CCSVI) plays a role in MS development, many patients underwent endovascular treatment (ET) of CCSVI.

“The results of this study are self-explanatory and mirror our experience with the few patients from our centre who have had treatment typically abroad. The results are clear: it is no miracle treatment. What we also need is some symptomatic outcome data and an economic analysis.”

“Whilst we are waiting for the results of prospective blinded trials we do not recommend that any MSer have this procedure outside of a clinical trial protocol. In addition, MSers should not be paying for the procedure either.”

**Vasillis Vassileopoulos**

Wednesday, January 30, 2013 1:00:00 pm

This study compared observational study published in 2006 against CCSVI. Let’s see why it’s not the best quality.

1. It is an observational study. Patients had the treatment somewhere and Italian neurologists gave them questionnaires to complete in their clinical protocol. The questionnaires were not anonymous.

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Google Trends

Jan 2000 – Apr 2015

**Interest over time**

Regional interest:

- Italy: 100
- Canada: 75
- Netherlands: 19
- Poland: 16
- United States: 13
- United Kingdom: 10
- Germany: 9

**View change over time**
Reasoning by analogy

"There is a lovely road that runs from Ixopo into the hills..."
Alan Paton, Cry, The Beloved Country, Ch. 1

My beloved country
HIV/AIDS Analogy

Four types of AIDS denialist:

1. The ‘dissident scientist’ who lends credibility
2. The ‘cultopreneur’ who peddles quack therapies
3. The ‘living icon’ or ‘long-term survivor’
4. The ‘praise-singer’ or ‘journalist’ or ‘politician’ who sows doubt about HIV causing AIDS

The HIV/AIDS community

1. Patient activists / organisers
2. Access to media
3. Conspiracy theories
“In a world in which anti-science appears to be on the increase, it is imperative that scientists improve how they engage with the general public about research.....”

Do you want to have regrets?
CCSVI-A. A call to clinicians and scientists to vocalise in an Internet age

Arie R. Gafson*, Gavin Giovannoni

Queen Mary University of London, Blizard Institute, Barts and The London School of Medicine and Dentistry, 4 Newark St, London E1 2AT, United Kingdom
Social networks are the key to the world


Pageviews by Countries

<table>
<thead>
<tr>
<th>Entry</th>
<th>Pageviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>United States</td>
<td>1425051</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>910368</td>
</tr>
<tr>
<td>Germany</td>
<td>206546</td>
</tr>
<tr>
<td>France</td>
<td>164612</td>
</tr>
<tr>
<td>Canada</td>
<td>102274</td>
</tr>
<tr>
<td>Australia</td>
<td>97053</td>
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<td>Ukraine</td>
<td>58060</td>
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<tr>
<td>Russia</td>
<td>59459</td>
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<tr>
<td>Sweden</td>
<td>35947</td>
</tr>
<tr>
<td>Spain</td>
<td>22645</td>
</tr>
</tbody>
</table>
Clinical practice?

What is your risk of developing PML?

RISK FACTOR:
Preexposure prophylaxis.
Small studies have suggested a reduced risk of PML in patients who are on prophylaxis.

Low PML risk
- 1 in 2,000
- 1 in 1,429
- 1 in 823
- 1 in 76

High PML risk
- 1 in 12

RISK FACTOR:
Prior exposure to JC virus, as indicated by the presence of JC virus antibodies.
The JC virus is present in most adults. The risk of PML is higher in patients with prior exposure to the JC virus, which is why we ask if you have been infected with the virus in the past.

Low PML risk
- 1 in 10,000
- 1 in 1,000
- 1 in 87

High PML risk
- 1 in 12

>1.5 million SlideShare views
Understanding your risk of PML on Tysabri

This page will give you an overview of the benefits and risks of Tysabri and allow you to calculate your risk.

[3 minute read]

The lumber puncture procedure

What to expect before, during, and after your lumbar puncture procedure.

[3 minute read]
EDSS
Online Assessment

The Expanded Disability Status Scale (EDSS) is the gold standard method of quantifying disability in multiple sclerosis.

This assessment should take between 5-10 minutes to complete and will allow you to calculate your own accurate EDSS score.

This should give you some independence from your neurologist, empowering you to monitor your own disease progression and relate it to the published data on MS.

www.clinicspeak.com

ClinicSpeak

Multiple Sclerosis Research
Barts and The London
School of Medicine and Dentistry

Tuesday, 30 July 2013

Clinic speak: should I start glatiramer acetate?

Question: Receiving intravit, US for 7 years, 1-2 years on interferon beta. Stable and progressive, no medication for 2-3 years, few symptoms once a year. I have been offered Copaxone by my consultant. Should I start Copaxone?

Answer: There is no one clear answer to this question. I need a lot more information and have numerous questions about that said 'best practice before being able to give advice'. Please note the emphasis is to give advice, I strongly believe the person who has the disease should make the final decision about what treatment to start. Please to the person who has the disease, with all its unpredictable and disabling, and to families with their role in effets and outcomes must, not me. My role, or more accurately the role of the MS team, is to make this process easier for them.

This clinic/survey is not dependent. I am often asked to see patients to a wide or 3rd options usually to give advice around disease modifying treatments (DMDs).
ClinicSpeak

An holistic approach to MS
Big issues

Control

Multiple sclerosis
228 responses

Are you aware of having any brain atrophy on your MRI?

- Yes: 44 (15%)
- No: 163 (71%)
- NA - no MRI: 17 (7%)
- NA - no MRI

Would you like to know if you had any brain atrophy on your MRI?

- Yes: 191 (84%)
- No: 3 (1%)
- No sure: 28 (12%)
- No sure

Would you like to know if you had progressive brain atrophy on your MRI?

- Yes: 164 (86%)
- No: 5 (2%)
- No sure: 27 (12%)
- No sure

If you had brain atrophy would you consider switching to a drug or DBT that had been shown to have an impact on brain atrophy?

- Yes: 166 (74%)
- No: 6 (3%)
- Not sure: 52 (23%)
- Not sure

www.ms-res.org
Why Grey Matter matters

Brain atrophy in MS: what are its consequences?

Brain atrophy, or shrinkage, occurs in the majority of MSers at all stages. Grey matter atrophy accelerates over time and with disease progression.

The brains of MSers shrink at a rate of 0.5-1.0% per year compared to a rate of between 0.1-0.4% in normal brains.

Brain atrophy, or brain shrinkage, in MS, as measured by MRI, is associated with disability and cognitive impairment.

Save your Grey Matter it really does matter.

Version 4.0, 29 September 2013.
Adoption
# Education

## Key milestones in the development of Fingolimod

<table>
<thead>
<tr>
<th>Year</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1992</td>
<td>Fingolimod (FTY720) first synthesized by Japanese scientists</td>
</tr>
<tr>
<td>1997</td>
<td>Fingolimod in-licensed by Novartis for clinical development</td>
</tr>
<tr>
<td>1998</td>
<td>First studies in man (Phase 1 trials) and subsequent start of transplantation trials</td>
</tr>
<tr>
<td>2003</td>
<td>Start of MS Phase II trial</td>
</tr>
<tr>
<td>June 2005</td>
<td>Presentation of Phase II study results followed by publication in NEJM 2006</td>
</tr>
<tr>
<td>Jan 2006</td>
<td>Start of Phase III FREEDOMS study in RRMS</td>
</tr>
<tr>
<td>May 2006</td>
<td>Start of Phase III TRANSFORMS study in RRMS</td>
</tr>
<tr>
<td>June 2006</td>
<td>Start of Phase III FREEDOMS II study in RRMS</td>
</tr>
<tr>
<td>July 2008</td>
<td>Start of Phase III INFORMS trial to assess suitability for treatment of PPMS</td>
</tr>
<tr>
<td>Dec 2008</td>
<td>Release of TRANSFORMS study results and presentation at AAN April 2009</td>
</tr>
<tr>
<td>Sep 2009</td>
<td>Release of FREEDOMS study results and presentation at AAN April 2010</td>
</tr>
<tr>
<td>Dec 2009</td>
<td>Regulatory submission to FDA and EMA (ROW submissions in Q1 2010)</td>
</tr>
<tr>
<td>Feb 2010</td>
<td>Results of Phase III TRANSFORMS &amp; FREEDOMS studies published in NEJM</td>
</tr>
<tr>
<td>Sep 2010</td>
<td>Approval by Russian Health Authority</td>
</tr>
<tr>
<td>Sep 2010</td>
<td>Approval by the US FDA for relapsing MS</td>
</tr>
<tr>
<td>April 2015</td>
<td>Negative PPMS (TRANSFORMS) Study</td>
</tr>
</tbody>
</table>
RESEARCH BLOG www.ms-res.org

"Drug: The Game"

Development Process: Why is it Slow

Publications
What do you call someone who has MS?

<table>
<thead>
<tr>
<th>Term</th>
<th>MS Blog</th>
<th>MS Society</th>
<th>Science</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>8%</td>
<td>8%</td>
<td>98%</td>
</tr>
<tr>
<td>PwMS</td>
<td>38%</td>
<td>68%</td>
<td>24%</td>
</tr>
<tr>
<td>MSer</td>
<td>52%</td>
<td>12%</td>
<td>0%</td>
</tr>
</tbody>
</table>
600 MSers

6 months

300 MSers

Year 1

300 MSers

Year 2

Year 3

300 MSers

Active tablet

Placebo tablet

6 months

60 MSers

30 MSers placebo tablet

6 months

6 months

30 MSers active tablet

6 months

LP1

LP2

LP3

Recruitment

Trial

Data analysis

2 years
Would you be prepared to have 3 lumbar punctures as part of this clinical trial? This applies to all MS'ers (relapsing and progressive); the question should be viewed from a perspective of if you had progressive MS would you be willing to have 3 lumbar punctures.

66%  
13%  
21%  

n = 127
Towards the incorporation of lumbar puncture into clinical trials for multiple sclerosis

Arlo A Gulara1 and Garic Gugven2

Multiple sclerosis (MS) is a chronic inflammatory disease of the central nervous system, which usually begins between ages 20 and 40. The duration and intensity of symptoms vary widely from person to person, with some experiencing minimal symptoms and limited disability, while others experience severe disability. While recent advances in the treatment of relapsing-remitting multiple sclerosis (RRMS) have been made, there is still a need for effective therapies to treat progressive forms of the disease.

The presence of oligoclonal bands in cerebrospinal fluid (CSF) is often seen in patients with MS, but the significance of these bands is not fully understood. A recent study aimed to investigate the potential role of lumbar puncture in clinical trials for MS by evaluating the presence and significance of oligoclonal bands in CSF.

In this study, lumbar puncture was performed on 100 patients with RRMS. The CSF samples were analyzed for the presence of oligoclonal bands using a sensitive and specific assay. The results showed that oligoclonal bands were present in 80% of the samples, indicating their potential use as a biomarker for MS.

The study also evaluated the impact of lumbar puncture on the patients' quality of life. The results showed a significant improvement in the quality of life for patients who underwent lumbar puncture, suggesting that this procedure may be a beneficial addition to clinical trials for MS.

In conclusion, lumbar puncture is a feasible and effective addition to clinical trials for MS, particularly in assessing the presence of oligoclonal bands in CSF. Further research is needed to fully understand the clinical significance of these bands and to determine their role in patient care.

References


Political Agenda
Self-management & Monitoring
Monitoring your own disease

SymTrac™ is a free app that helps people with MS track general wellbeing and symptoms over time. The data recorded can be viewed in easy-to-read charts and shared with MS specialist teams to make the most of vital consultation time and support decision making.

SymTrac™ has been accepted onto the NHS Health Apps Library.

View terms and conditions here.

Development of the App has been funded by Novartis.
Can 'smartphones' monitor disease progression in Multiple Sclerosis?

Sashank Prasad, MD
Charles Jensings, PhD
Ravi Rameshchandran, PhD
Harvard Medical School

on behalf of
Multiple Sclerosis Consortium for the Development of Smartphone Support Systems (MSCODES3)

Background
An unmet need for accurate assessment of disease progression in Multiple Sclerosis is critical to delivering appropriately individualized care for patients with Multiple Sclerosis.

A paradigm shift?
Smartphones offer the potential for high-quality, real-time, longitudinal data capture. This technology may fundamentally transform traditional methods of clinical monitoring, which often rely on subjective report of symptoms rather than objective measures of disease.

Potential data streams may include several domains:
- **Healthcare:** Blood pressure, heart rate, medication adherence
- **Activity:** Walking speed, general activity level
- **Environment:** Indoor and outdoor temperature, noise levels
- **Location:** GPS-based location tracking
- **Patient-reported outcomes:** Fatigue, mood

These data may help detect subclinical changes in natural settings, enabling novel avenues of clinical therapeutic studies.

Methods
An interdisciplinary consortium established a group of clinicians and scientists with expertise in:
- Multiple Sclerosis
- Cognitive Psychology
- Kidney function
- Computer Science
- Regulatory Affairs

The consortium intends to develop a smartphone application to track disease progression and to make its technologies available to an open-source basis.

Project development
- Develop a diverse suite of mobile applications
- Design and test fidelity of data encryption, transfer and storage

Prototype completed
- HTC Sensation Android smartphone
- Good Technology Mobile Device Management
- Custom platform to present apps on rotating schedule
- Anticipated participation: 100 patients

Prototype
- Suit of custom-designed “apps”
  - Trail-making tasks A & B
  - Attentional processing
  - Continuous performance task
  - Visual-verbal and visuospatial tasks
  - Auditory memory test
  - Brixton memory test
  - Verbal assessment of cognition
  - MS Quality of Life Inventory questionnaires
  - Parental assessment of quality of life
  - Subjective temperature perception
  - Subjective assessment of study participation
  - Previously collected time-series and local weather data

Funding sources
- Vertex Pharmaceuticals

Adapt or die?
Analogue or digital?

Dinosaur or wired?

Benefits & Consequences
Conclusions

• Social Media / eHealth / eMonitoring are here to stay
• Adoption is occurring very rapidly
• Advantages are obvious
  • Improved efficiency (cost and time effective)
  • Better outcomes
  • Higher satisfaction
• Hurdles to adoption are not insurmountable
  • Privacy and data protection
  • Medico-legal issues
• It is hard to ignore the positives; ask your patients?
  • Change agent