

Paraplegie Community

The online Community for people with spinal cord injury, their relatives and friends

www.community.paraplegie.ch

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A story from the Community...

“I've been sitting for 12 years now - para, th12 complete. And actually I think I've managed quite well so far. Lately, however, there have been thoughts about how my life would have gone on without the accident and also thoughts about the accident (although they weren't there for a while). And through that also again the thoughts of this finality, etc. How do the others here deal with it?”



Markus40

Contributor

A story from the Community...

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Markus40

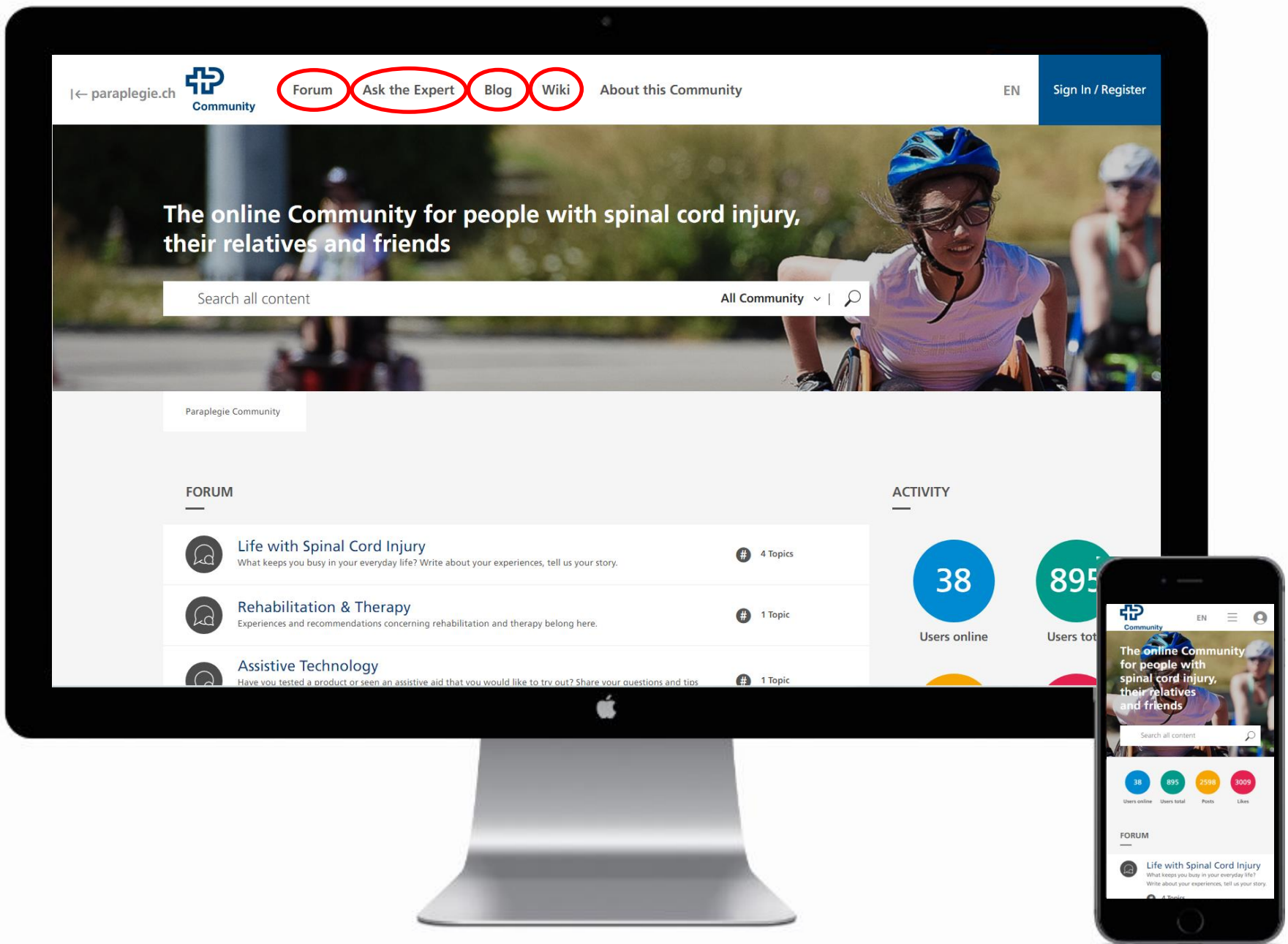
Contributor

Why this Community?

- to provide an online service for people with SCI
- to foster knowledge exchange around SCI
- to provide knowledge about SCI and disability
- to gain various views and answers in a short period

Why is the Community “better” than Facebook?

- anonymous
- protected: no advertisement, personal data stay with us etc.
- moderated: no unqualified posts or wrong information
- every question receives an answer
- 1-2 new blog articles every week
- free medical advice
- in four languages: DE, FR, IT, and EN



Forum: typical peer-to-peer exchange

I need your tips on how to keep warm in winter



Thessy

Contributor

I am a quadriplegic and therefore very sensitive to cold. I wear thick underpants from the company Rollitex www.rollitex.de. They are warm and sit well.

great link, I didn't know it yet, thank you very much!



Thessy

Contributor



Nichtsdestotrotz

Contributor

Ask the Expert: experts from SPC at your service



Ptitefleur13
Auteur

✓ Ossification des muscles

Bonjour,

Mon frère est à Notwill depuis 2 mois et développe cette problématique. Etant à l'étranger pour études, je n'ai pas la possibilité de me renseigner auprès des médecins. Auriez-vous une documentation ou un article sur le sujet afin de comprendre à quoi il fait face ?

D'avance merci de votre aide.



ANKS
Dr. Online

✓ Betreff: Ossification des muscles

Bonjour Petitefleur13 et tous les autres

Je suis médecine et travail déjà depuis longtemps dans la spécialité de la paraplégie et avec le problème ou la complication des ossifications. Les ossifications sont un phénomène qui arrive dans 10 à 30 pourcent des toutes les paraplégiques. Nous ne pouvons pas vraiment expliquer pourquoi une ossification arrive. Dans le moment d'une ossification on commence souvent et s'il y a pas de contradiction avec les thérapies des anti-inflammatoires. L'effet de cette médication est moyen et pas complètement compris. Souvent on peut aussi ajouter des autres thérapies de la physiothérapie ou de la thérapie physiquement. Tous ces décisions sont vraiment individuelles. Finalement le processus de l'ossification se termine spontanément.

J'espère que vous avez trouvé assez de réponses pour votre question. Autrefois tu peux demander d'aspect plus spécifique.

Tous les bien

ANKS

Blog: weekly new articles on SCI topics worldwide

BLOG

The Ableism of Environmental Protection

Reducing pollution but sadly also the rights of people with disabilities

Thursday

[View article →](#)

Commerce with wheelchair users?

These promotional wheelchair videos will warm your hearts. Maybe.

a week ago

[View article →](#)

Playgrounds for All

Barrier-free and inclusive for all abilities

3 weeks ago

[View article →](#)

Wiki: evidence-based medical information on SCI written by SPC health professionals for a lay audience

TRAVELLING WITH SPINAL CORD INJURY

Wheelchair users are almost as mobile as people without a disability, at least in Europe and North America. But when it comes to travelling Africa, certain regions of Central and South America as well as some Asian countries, a traveller with a spinal cord injury might have to lower her or his sights with regard to comfort and accessibility. However, the sometimes deficient infrastructure is compensated by the tremendous willingness to help of the locals. The only challenge that might remain is the language barrier for guiding the highly motivated helping hands with regard to purposeful interventions.



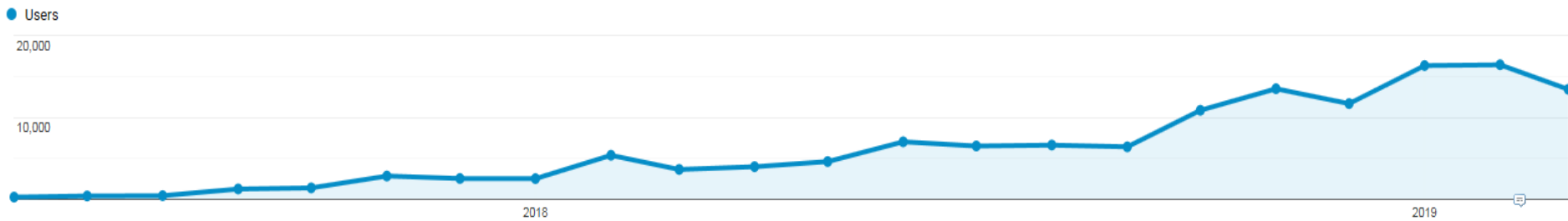
Street in Bhaktapur/Nepal

Therefore it should be a part of every holiday preparation to gather sufficient information about accessibility of your means of transportation (and hotels). The Swiss Paraplegic Association offers fact sheets for many situations on their website (www.spv.ch/en/publications/leaflets). Some are available also in English, others only in German and French.

Depending on the means of transportation, various problems can occur in different parts of the world. This article therefore focuses on the possibilities

The Community is growing...

Currently 10,000 – 20,000 users per month.



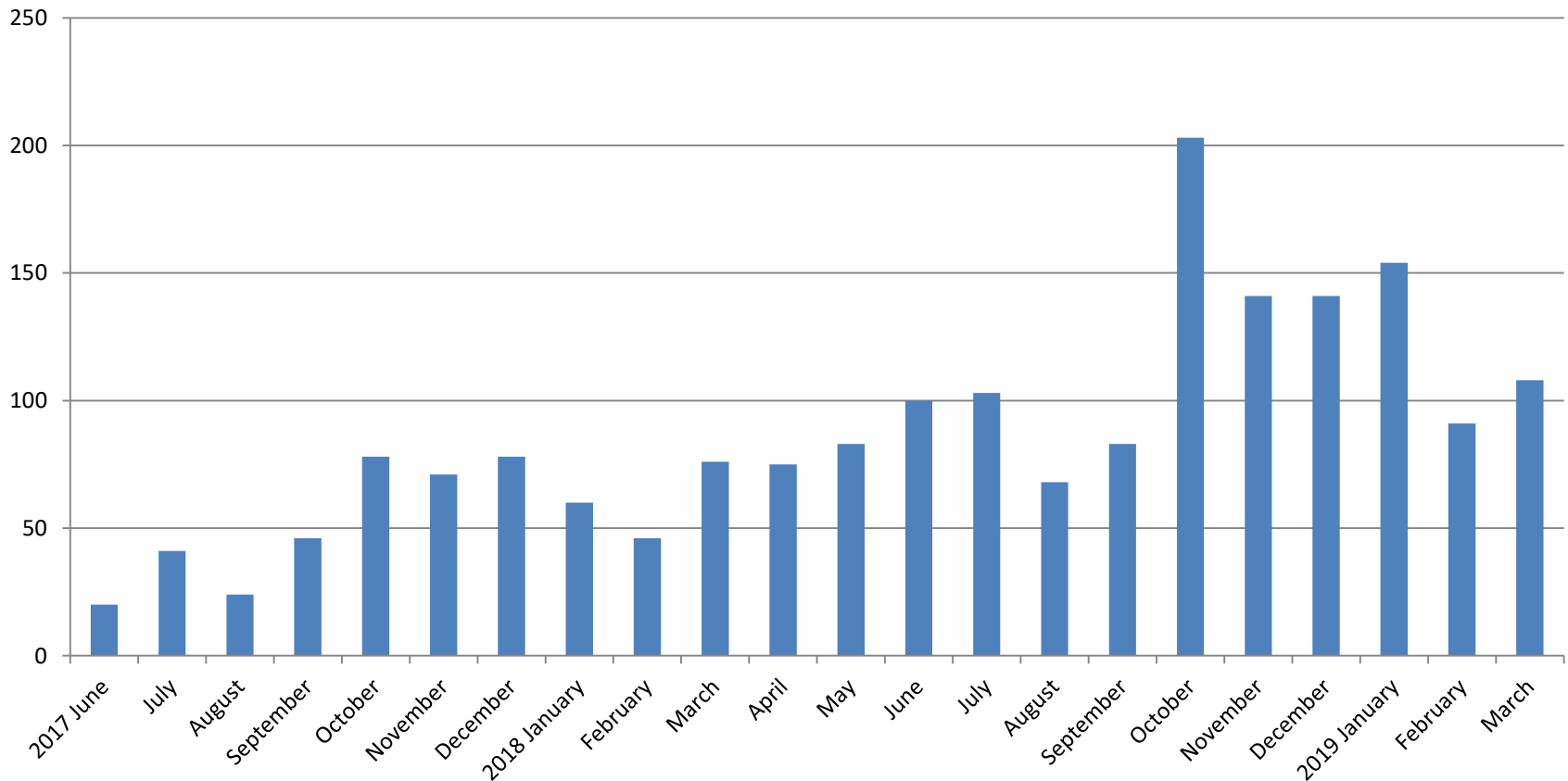
Users
129,788



Time range: 01.06.2017-31.03.2019; source: Google Analytics

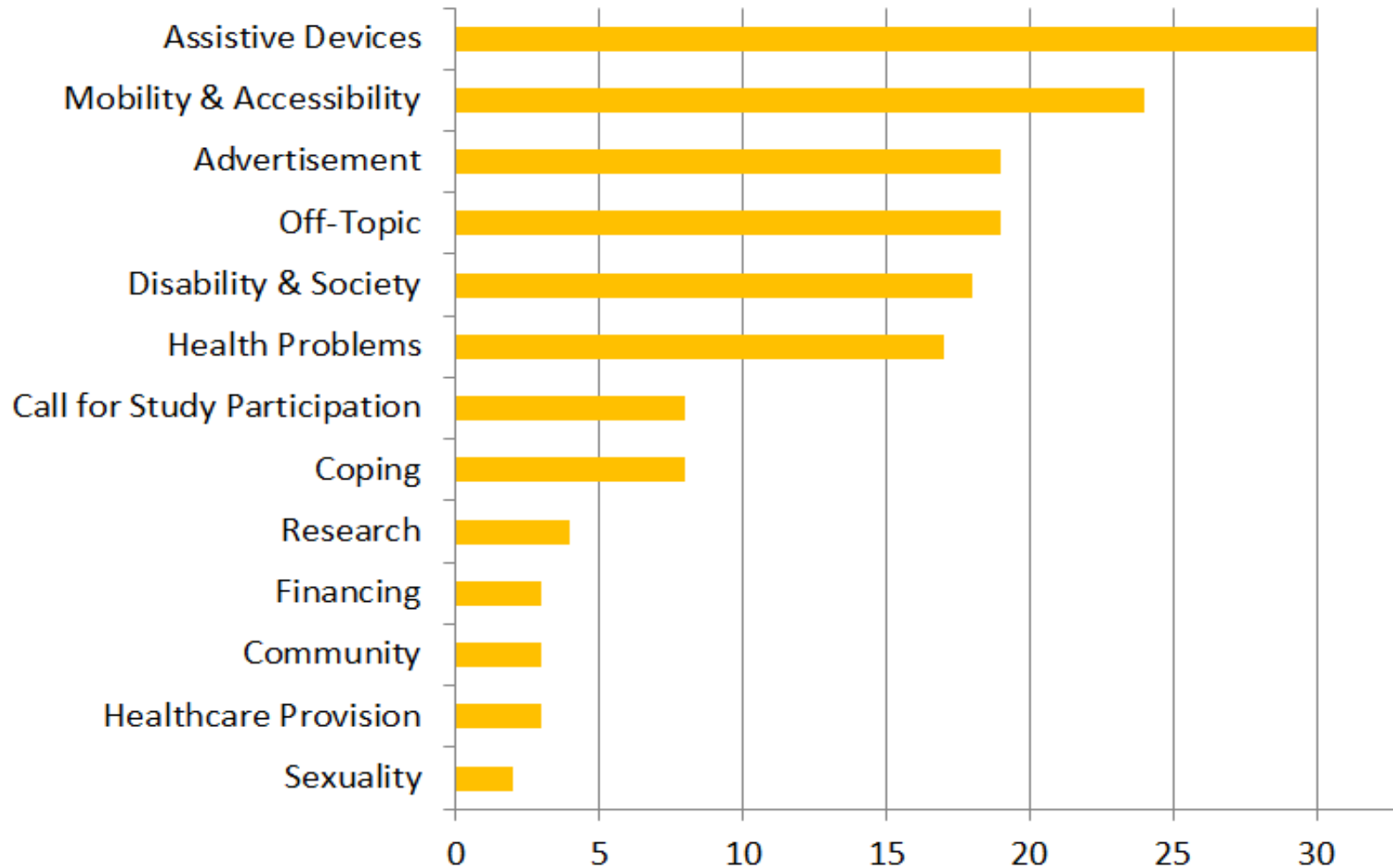
... and active!

Regularly more than 100 posts per month.
Over 2,600 posts in less than two years.



Time range: 01.06.2017-31.03.2019; source: Community backend

Most referred topics in the Forum



Time range: 01.06.2017-25.01.2019; source: Community frontend

Challenges when building an online Community

- privacy vs. visibility
- moderation requires 24/7 service
- multilingualism multiplies the efforts
- the “critical mass” is difficult to reach for SCI
- social media like Facebook are big competitors

Tips for building an online Community

- start small – you can always enlarge
- users seem to appreciate the opportunity to ask an expert
- engage not only online, but also offline
- try to attract superusers and create a personal bond
- be patient – Rome wasn't built in a day ;)

The exchange is very good for me.
I was able to implement some of
the tips in my everyday life and I
gained quality of life through it.



odyssita

Expert

I wish more
people would
sign up every
day

We are a community
of destiny and share
beautiful and sad
things



cucusita

Wise Contributor



Francescolife

Expert

One discussion...



Verarbeitung [1 2 3]

von Markus40 am 15.10.2017 15:58 • Neuester Beitrag am 03.04.2018 21:16 von cucusita

20

6598



Kurse und Seminare für Menschen mit Querschnittläh... [1 2]

von knowhow am 19.01.2018 11:48 • Neuester Beitrag am 01.04.2018 12:30 von ADMIN Johannes

12

8659



Thermoregulation im Winter [1 2]

von Thessy am 05.11.2017 13:06 • Neuester Beitrag am 27.03.2018 15:07 von fritz

13

7056



Wie barrierefrei ist Deine Stadt? [1 2]

von ADMIN Johannes am 25.01.2018 10:39 • Neuester Beitrag am 01.03.2018 09:04 von Slicks

13

13566



„Du bist so tapfer!“ – Welche Sprüche nerven Euch? [1 2]

von ADMIN Johannes am 18.12.2017 22:12 • Neuester Beitrag am 10.01.2018 09:07 von cucusita

6

4869



57 Jahre Paraplegiker

von Rolfd am 14.09.2017 16:55 • Neuester Beitrag am 09.01.2018 15:43 von Rolfd

9

6817



Rollstuhlgängige Wohnung direkt am Genfer See zu v... [1 2]

von staldi am 11.12.2017 13:58 • Neuester Beitrag am 13.12.2017 11:16 von staldi

2

3035



Fatigue / Trainingsintoleranz [1 2]

von odysita am 07.11.2017 16:54 • Neuester Beitrag am 12.12.2017 13:47 von nevea

18

6859

... can be helpful for thousands of people!



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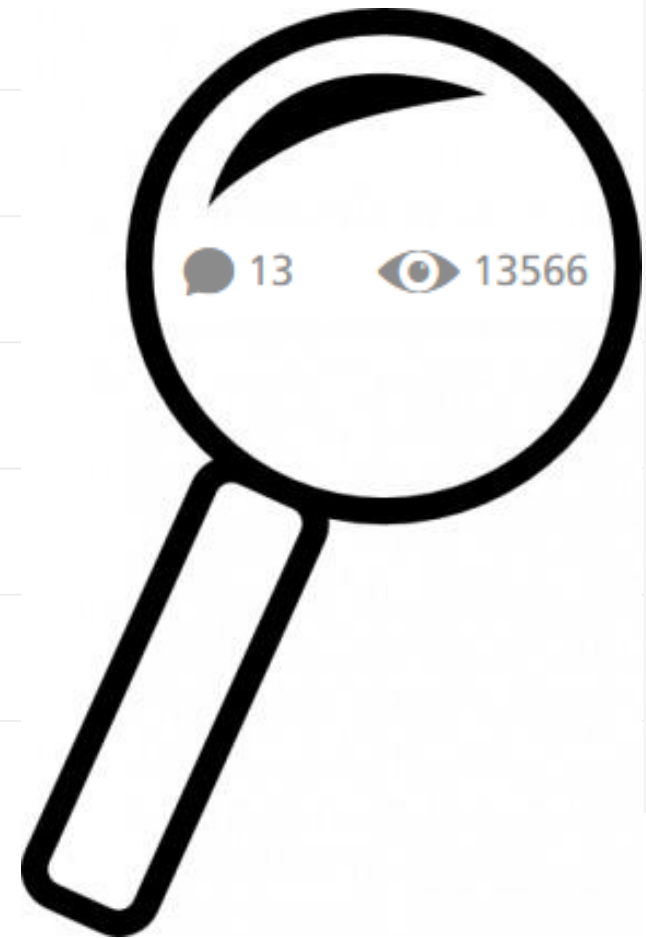
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A large, shiny, metallic ring sculpture, possibly made of polished metal, stands prominently on a grassy hill. The ring is highly reflective, mirroring the surrounding landscape and sky. The background features a clear blue sky with scattered white clouds and a line of green trees on the horizon. The overall scene is bright and open.

Your experience is valuable – it could help others.

Join the online Community!


www.community.paraplegie.ch

Interesting discussion on “political correctness”

<https://community.paraplegie.ch/t5/Leben-mit-Querschnittl%C3%A4hmung/Behinderung-Erkrankung-oder-Wie-seht-Ihr-Euch/m-p/5424>

Users by country

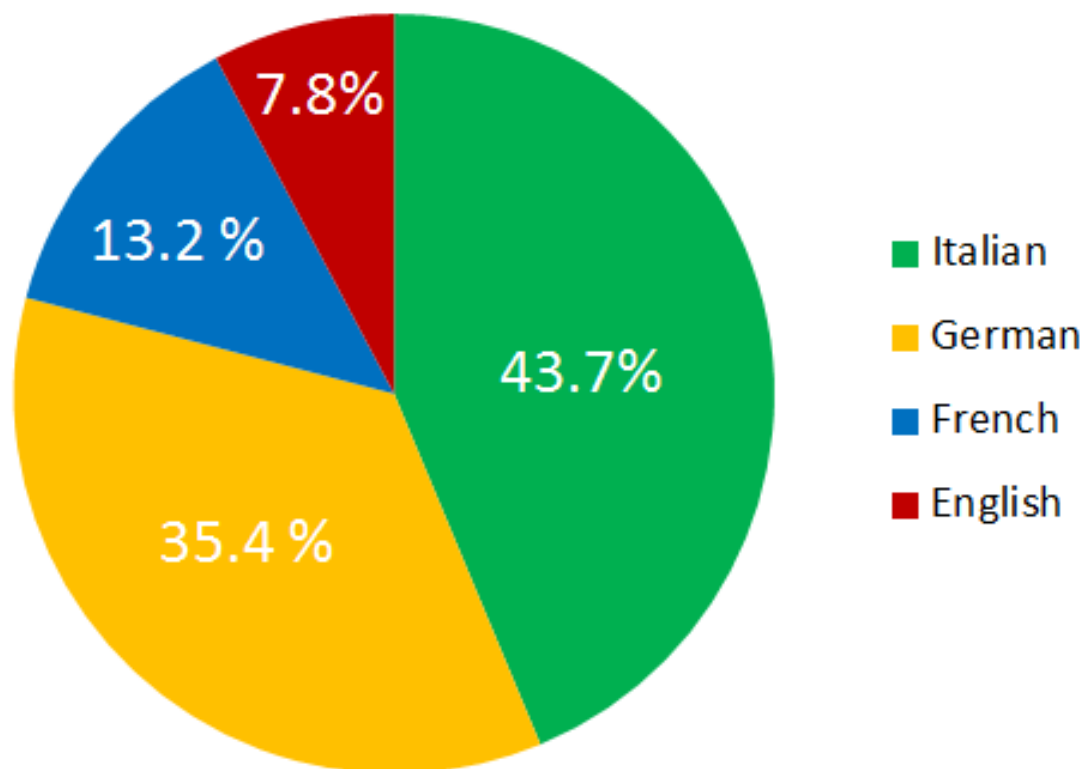
Italy has passed Switzerland because of Google rankings.

Country	Users
 Italy	41,793
 Switzerland	28,952
 Germany	8,642
 France	8,242
 United States	2,652
 Austria	1,695
 Canada	990
 Belgium	729
 United Kingdom	664
 India	374

Time range: 01.06.2017-25.01.2019; source: Google Analytics

Users by language

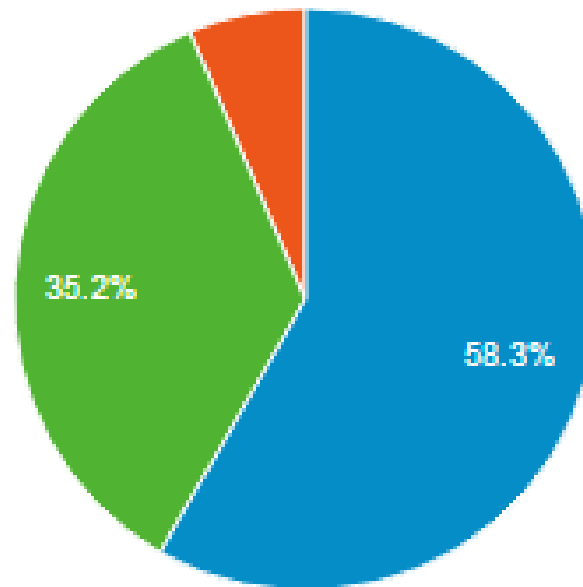
Italy has passed German.



Users by device

Mobile more important than desktop.

■ mobile ■ desktop ■ tablet



Google rankings

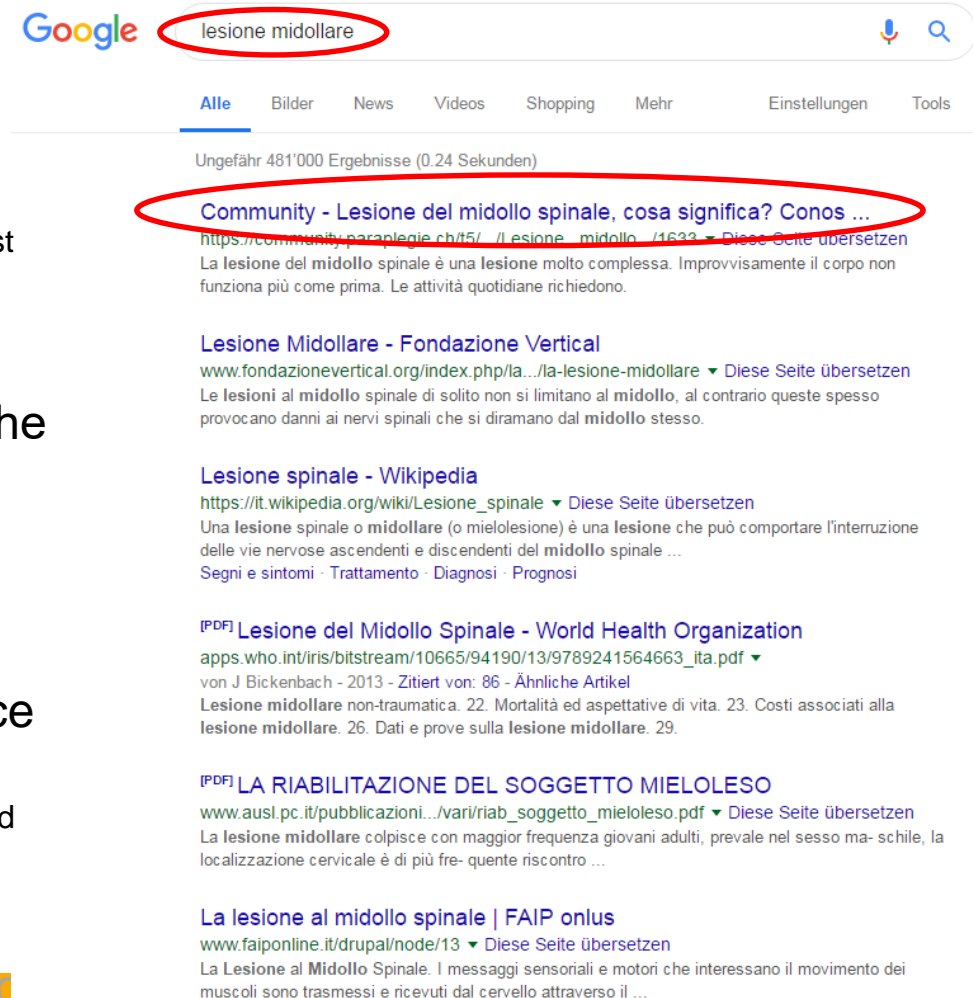
Community on first place for important Italian and French keywords.

Italian keywords:

- “lesione midollare”: 1st place
- “lesione/i del midollo spinale”: 1st place
- “lesione spinale”: 1st place
- “svuotare l’intestino” (= “empty the bowel”): 1st place
- etc.

French keywords:

- “lésion médullaire”: 1st & 2nd place
- “paralysie médullaire”: 2nd place
- “lésion de la moelle épinière”: 3rd place
- etc.



The screenshot shows a Google search for "lesione midollare". The search bar and the first result are circled in red. The first result is from the "Community" website, titled "Lesione del midollo spinale, cosa significa? Conos ...". Below it are other results from "Fondazione Vertical", "Wikipedia", "World Health Organization", and "FAIP onlus".

Google lesione midollare

Alle Bilder News Videos Shopping Mehr Einstellungen Tools

Ungefähr 481'000 Ergebnisse (0.24 Sekunden)

Community - Lesione del midollo spinale, cosa significa? Conos ...
<https://community.paraplegie.ch/t5/-/il-lesione-midollo-/1633> ▼ Diese Seite übersetzen
La lesione del midollo spinale è una lesione molto complessa. Improvvisamente il corpo non funziona più come prima. Le attività quotidiane richiedono.

Lesione Midollare - Fondazione Vertical
www.fondazionevertical.org/index.php/la.../la-lesione-midollare ▼ Diese Seite übersetzen
Le lesioni al midollo spinale di solito non si limitano al midollo, al contrario queste spesso provocano danni ai nervi spinali che si diramano dal midollo stesso.

Lesione spinale - Wikipedia
https://it.wikipedia.org/wiki/Lesione_spinale ▼ Diese Seite übersetzen
Una lesione spinale o midollare (o mielolesione) è una lesione che può comportare l'interruzione delle vie nervose ascendenti e discendenti del midollo spinale ...
Segni e sintomi · Trattamento · Diagnosi · Prognosi

[PDF] Lesione del Midollo Spinale - World Health Organization
apps.who.int/iris/bitstream/10665/94190/13/9789241564663_ita.pdf ▼
von J Bickenbach - 2013 - Zitiert von: 86 - Ähnliche Artikel
Lesione midollare non-traumatica. 22. Mortalità ed aspettative di vita. 23. Costi associati alla lesione midollare. 26. Dati e prove sulla lesione midollare. 29.

[PDF] LA RIABILITAZIONE DEL SOGGETTO MIELOLESO
www.ausl.pc.it/publicazioni.../vari/riab_soggetto_mieloleso.pdf ▼ Diese Seite übersetzen
La lesione midollare colpisce con maggior frequenza giovani adulti, prevale nel sesso maschile, la localizzazione cervicale è di più frequente riscontro ...

La lesione al midollo spinale | FAIP onlus
www.faiponline.it/drupal/node/13 ▼ Diese Seite übersetzen
La Lesione al Midollo Spinale. I messaggi sensoriali e motori che interessano il movimento dei muscoli sono trasmessi e ricevuti dal cervello attraverso il ...