Duchenne Muscular Dystrophy

Duchenne muscular dystrophy is the most common fatal genetic disorder diagnosed in childhood, affecting approximately 1 in every 3,500 live male births (about 20,000 new cases each year). Because the Duchenne gene is found on the X-chromosome, it primarily affects boys; however, it occurs across all races and cultures.
Duchenne Parent Projects

Since 1994 Duchenne Parents in several countries set up national organisations because they decided:

To take their responsibility and make a change in the future of their sons and their DMD peers
To take action and not consider themselves as victims of this disease
To finding a cure and viable treatments for Duchenne and Becker Muscular Dystrophy.
To raise awareness and money for research to help treat, and eventually cure, DMD
National

Awareness raised from 2% - 52%
Guidelines for Optimal care
Funding Research $12 million/year
More than 200 research projects
Investment in Industry
Partnership with clinicians and scientists
Successful Lobbying
DMD Patient registries
Promising clinical trials ongoing
United Parent Projects Muscular Dystrophy
Set up in 2001 by 8 National Duchenne Parent Projects

Dedicated
to finding a cure and viable treatments for DMD
to promoting good standards of care around the globe
to informing and empowering parents around the globe

Collaboration
More efficient use of collective experiences and resources
Serve as a Global Duchenne Parent platform

Duchenne-community.org
Serve as a Global Duchenne Parent platform

How can we reach parents, organised and not organised, around the globe?

How can we empower parents to raise their voice?

How can we help parents to get organised in their own country?
Promoting good standards of care

Guidelines of optimal care for DMD boys since 1997

Well informed parents are the best advocates for their children.

Empowerment is key!

Parents ‘treat’ their children 24/7, 365 days a year, they need good and understandable instructions

Improve medical care in their country bottom-up
Online Community

Summer 2006 we decided to have a place online where all parents would:

Feel at home: welcome and “safe”

Find reliable information on
  their own level (science and stage of the disease)
  care and research
  how to set up an organisation

Preferable in their own language

Be able to find other parents and parent groups
  from other countries
  countrymen
Some ‘small’ problems:

We knew what we wanted

We had no budget (<10,000 euro)

We had no knowledge about on-line communities
Dutch company with extensive experience in online communities

No experience in patient communities

Very dedicated

Offered to sponsor!
INTRODUCTION VIRTUAL COMMUNITIES

“For the People
Of the People
And By the People”

By: OOiP (www.ooip.nl)
A community is a community if

1. The group has something in common (problem/interest/desire/target) and...

2. the common thing is something that can occupy the group on daily basis and...

3. the group is willing to communicate about this and...

4. by contact and information (threw contact) is being helped by the common.

..an online community if

1. The group is online and...

2. the internet is the most important medium in aspect of the common
Why are people joining a community?

Non-public and public online community participation: Needs, attitudes and behavior

<table>
<thead>
<tr>
<th>Reasons for joining</th>
<th>Posters (%)</th>
<th>Lurkers (%)</th>
<th>p</th>
<th>$\chi^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Get answers to questions</td>
<td>70.3</td>
<td>62.1</td>
<td>0.018</td>
<td>5.558</td>
</tr>
<tr>
<td>Tell stories or participate in conversations</td>
<td>55.5</td>
<td>23.7</td>
<td>0</td>
<td>72.092</td>
</tr>
<tr>
<td>Access to expertise</td>
<td>51.9</td>
<td>41.1</td>
<td>0.004</td>
<td>8.348</td>
</tr>
<tr>
<td>Be a community member</td>
<td>48.9</td>
<td>24.2</td>
<td>0</td>
<td>44.172</td>
</tr>
<tr>
<td>Make friends</td>
<td>48.6</td>
<td>31.5</td>
<td>0</td>
<td>21.049</td>
</tr>
<tr>
<td>Enjoy myself</td>
<td>46</td>
<td>32.9</td>
<td>0</td>
<td>12.551</td>
</tr>
<tr>
<td>Offer my expertise</td>
<td>36.5</td>
<td>12.8</td>
<td>0</td>
<td>46.136</td>
</tr>
<tr>
<td>Get empathetic support</td>
<td>35.8</td>
<td>23.7</td>
<td>0.001</td>
<td>11.649</td>
</tr>
<tr>
<td>Build professional relationships</td>
<td>14.4</td>
<td>7.8</td>
<td>0.008</td>
<td>6.955</td>
</tr>
<tr>
<td>Entertain others</td>
<td>11.6</td>
<td>2.7</td>
<td>0</td>
<td>15.515</td>
</tr>
</tbody>
</table>

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Tools of a community
Profiles

**camo135**

**Real name:** Camilla  
**Hometown:** Helsinki, Finland  
**Current Location:** Helsinki, Finland  
**Join Date:** TravBuddy member since June 17, 2007  
**Contributions:** camo135 has written about 8 places and shared 67 photos, meeting new people, sharing travel tips and blogs

**Future Travels**  
**London, United Kingdom**  
visiting London with the family =D  
**Sydney, Australia**  
**Byron Bay, Australia**  
**Queensland, Australia**  
**Victoria, Australia**  
catching up with friends =D  
**Sydney, Australia**  
**South America**  
this is definately a continent i need to explore! i'm hoping to be able to go year 2009 (for half a year, or a year) for travelling and working =D

**Countries I've Traveled To**  
Australia, Austria, Croatia, Cyprus, Denmark, Estonia, Fiji, Finland, France, Germany, Gibraltar, Greece, Italy, Monaco, Netherlands, New Zealand, Singapore, Spain, Sweden, Switzerland, Turkey, United States

**Languages Spoken**  
swedish, english, finish and studied spanish... cant really speak it tho (; ooooh and then i can say hello in about 15 more languages ;D

**Interests**  
having fun!! travelling, meeting new people, trying new things, hanging with friends, snowboarding, wakeboarding, getting smashed by waves when trying to surf (;, scuba diving, havin sum more fun, kickboxing, partying.
Message boards

De dollar... Hoe diep gaat hij zinken?

**matthijst**
In a New York State of Mind:

Dollar is weer vorige aan het dalen. Op het moment op 2h laagste punt in 20 maanden.

Hoe diep gaat ie zakken? 😐

dear en-te-gen (bw.)
sk-we-se (bw.)
to alle tijd

**longinus**
Hollander:

Bij elektronika blijft de wisselkoers één dollar is één euro, maakt niet veel uit dus.
Hooguit merken we er wat van in de olieprijzen.

Tering, wat gaat de tijd snel.
Poster van de 43.999.999 post op FOK?

**Kogando**

Waarom ben je daar blij om? Grote Nederlandse bedrijven zoals Heineken hebben er veel schade van doordat met name Amerikanen minder bier kopen omdat dit duurdere is. 😐

Het is alleen leuk als je zelf dingen met de euro koopt in dollarlanden. 😊

Ik heb een online test gedaan waaruit bleek dat ik al jaren in come lig. 😱

**Public_NME**

Come on you Whiter!

---

**aan:**

Op donderdag 30 november 2006 11:10 schreef Kogando het volgende:

Het is alleen leuk als je zelf dingen koopt met dollars 😐

Of op vakantie gaat naar de states 😐

The black and white you'll never pass, stick yer blue flag up yer arse!
They know on the Continent that European football without the English is like a hot dog without the mustard! Sir Bobby Charlton

**Kogando**

---

De dollar... Hoe diep gaat hij zinken?
Polls

Your Opinion
Do you ship Cargo?
- Yes
- No
Submit
# Online Inquiry

## Online-enquête

1. Wat vindt u van de volgende eigenschappen van de igus website?
   - Mee eens
   - Deels mee eens
   - Mee oneens
   
<table>
<thead>
<tr>
<th>Eigenschap</th>
<th>Mee eens</th>
<th>Deels mee eens</th>
<th>Mee oneens</th>
</tr>
</thead>
<tbody>
<tr>
<td>Makkelijke navigatie</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overzichtelijkheid</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Geslaagde lay-out</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Snelle downloadtijden</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Goede zoekfunctie</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uitgebreide productinformatie</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Wat is uw algemene indruk van de website? Druk uw waardering uit, varierend van uitstekend tot onvoldoende.
   - Uitstekend
   - Goed
   - In orde
   - Voldoende
   - Matig
   - Onvoldoende

3. Zou u de igus website aan andere mensen aanbevelen?
   - Ja
   - Nee

4. Hoe vaak uitft u naar de igus website?
   - Elke dag
   - Elke week
   - Elke maand
   - Elk kwartaal
Expand Your Cycling Horizons

By Dean Schott

Discover adventure on your bicycle by doing a one-day invitational ride or a multi-day tour of Illinois. The rides give bicyclists the opportunity to explore new terrain, enjoy new experiences, meet other bicyclists and learn about the state’s great diversity all at an easy pace.

Each year bicycle clubs, charities, towns, chambers of commerce and other groups around the state invite bicyclists of all ages and abilities to come ride in their areas. Any easy way to find a ride or tour in your area is to go to the website of the League of Illinois Bicycles (LIB), www.bikelib.org.

The site lists the rides by month and provides details on dates, locations, distances, costs, goodies and how to register. Most are one-day events occurring from May to October. But for the dedicated, hardy cyclists, invitational rides are available during the colder months as well. Some rides or tours can last a weekend or a week.

Ride sponsors have a field day naming the rides, such as A Red Flannel Affair in St. Joseph, Folks on Spokes in University Park, Tour de Stooges in Lebanon, Udder Century in Union, Chase the Moon in Aurora, Bike Psychos’ Century in Coal City and the Pumpkin Pie Ride in Ottawa.

These are all one-day invitation rides of varying distances, depending on the choice of the rider. The events usually provide rest stops where you can snack and fill your water bottles. They also provide sag vehicles which travel the course to help cyclists who have a mechanical breakdown or can’t go on for any reason. Some rides also provide free t-shirts, a meal at the end of a ride, a goody bag and entertainment.
Personal messages & comments

New message

To: Victor de Pous

Submit

jojo55 says:
Congrats on ur award!!
Posted on: Aug 07, 2007

Hregina says:
There are a few good festivals here in Norway actually. Not the size of Rock am Ring, Glastonbury or Roskilde, but with great locations, so if the weather is good it's great to be there. The best ones are: Øya festivalen this week(end) in Oslo, Quart festivalen in Kristiansand (South) And Hove Festivalen in Arendal(south)The last two has already finished. Unfortunately it was raining all the time. Besides that we have a brilliant food festival here in my hometown called Gladmaten. This was last week, and guess what....It was raining. In two weeks we will have the local Music-festival here in Stavanger called Pulpit. Unfortunately there are no International bands this year, so i'm not planning to attend. Are there any good festivals in Amsterdam (Holland)?
Posted on: Aug 06, 2007

misspeazze says:
Thank you for your comments :-) 
Posted on: Aug 06, 2007
Reactions, reviews and interviews

Julien Constancia stond op scherp

Kijk aan. De beerpunt die Julien Constancia heet gaat langzaam open. Onderzoekers op de zaak en een regionaal dagblad. Julien kreeg in 2004 twee jaar extrastraf kort te wonen wegens een gewapende overval op een supermarkt in Breda. Twee kassierekers een plastic pippa tegen het hoofd zetten en 3500 euro mee graven. Maar dan wel netjes 'dankjewel' zeggen. Dat dan weer wel. Zowel de redactiers als de behandeling psycholoog onder de Veluwse zaken dat Julien 'zonder behandeling opnieuw goed in de fout zou kunnen gaan'. Of hij die behandeling heeft gekregen, is niet bekend. Dat hij opnieuw goed de fout in is gegaan, mag inmiddels nagenoeg bekend zijn. Nu die bekendheid nog. De pippa is er in ieder geval van overtuigd de dader te pakken te hebben, ondanks het feit dat Julien ontkent en bij zijn aanhouding een heel rustige, zelfs wat lachende indruk maakt. "Niet de houding die je verwacht van iemand die verdacht wordt van zo'n vreselijke misdaad. Of hij heeft het niet gedaan of er is iets helemaal mis met hem," aldus zijn advocaat. Wij gakken op het laatste. Overigens, Jesse heeft er misschien niets aan, maar dit land wordt wel steeds verliezer. En nou jullie weer...

Fleischbaun | 04-12-06 | 12:50 | Link | Comments (98)

Reacties

"Hij zou liden aan 'zelfverslaving' en 'sociaal normfobie' en zou opvallend geïnteresseerd zijn in apen en criminaliteit."

R.C.Q 04-12-06 @ 12:52

Juist met dat laatste heeft hij zichzelf verraden. Echt het "werk" van een totaal verstrikt getuigde buiten de samenleving opererende kruidnoot.

TyRester @ 04-12-06 @ 12:53

---

Poker Flat volume 5 - Bets 'n' Bluffs

door ed:win, gepubliceerd op donderdag 30 november 2006, 2642x bekeken
Newsletters

MEMBER UPDATE
September 2007

Where will you travel this Autumn?

Mesmerizing colors, mild temperatures, and fewer crowds are only some of the reasons we are drawn to autumn travel.

Tell us about your fall travel plans in our Autumn Travel Forum.

1. Fall Foliage

A full 37% of travelers are planning a trip to view the fall foliage this year, according to a recent TripAdvisor traveler survey. Take a trip to one of these amazing destinations and enjoy the rich colours and crisp air of autumn.

- Eastern Valleys, Norway
- Bohemia, Czech Republic
- Swiss Alps, Switzerland
- Munich, Germany
- Vermont, USA

Top 10 Sunny Sojourns

Not ready for cooler fall weather? You can still soak up the sun's rays! Check out our top picks for perennially sunny destinations.

1. Tenerife, Canary Islands, Spain
2. Cannes

2. Sports Season Excitement
Networks

Miriam’s Connections (39)

Dylan Alling
Concept Developer / Copywriter

Olger Kersboom
technical advisor at clockwork and Marketing and Advertising Consultant

Niek Schroten
Architect at Clockwork

Freek Bijl
Business Consultant at Clockwork

Elfried Klarenbeek
strategy director at Clockwork

Gaby Siera
Owner, Beautiful Lives

Ody Blankendaal
Mobile Marketing Consultant / Business Analyst at Clockwork and founder of TopSkinz

Deborah Knijnenburg
User Experience Consultant at Clockwork Ordina

Marieke Soons
Publisher at WEKA Uitgeverij

Richard Boogaard, van den
Consultant at QIH

Ilonka Kupecz
Sponsor Coordinator at Endemol Nederland

Eveline Van Der Herberg
Market Researcher at Friesland Foods Western Europe

Jan Commandeur
community consultant at OOP

Kasimir Landheer
Interactive Marketeer at Clockwork

Sander van der Putten
Creative Development Team Lead at Clockwork

Marc De Boer
Internet architect for Clockwork B.V.

Eppo Luiken
Consultant interactive marketing

Gert Van Exel
Owner, Krabbelaar

Marieke De Ruiter
Global Insight Manager Philips Lighting

Hans Mestrum
Advisor/Teacher (leergroepbegeleider) at Orion College

View Sander’s profile

Business Consultant at Clockwork
NFYB

New times demand new conventions. In a world where twitter and facebook and blogs can spread an idea around the world in a few seconds, how do you have a conversation with someone in confidence?

Just say NFYB ("not for your blog.")

Just like safe sex, it might not be romantic, but it’s something we need to talk about. So talk about it. The presumption is rapidly changing. It used to be that all emails or whispered hallway discussions were ‘off the record.’ Now, more and more, there is a bias to post/twit or share. “NFYB” clears the air.

When everyone is a journalist, most things are on the record.
Calender tools

1st September - 30th September
Location: Beijing
From: 1st September
Until: 8th September

4th
My Calendar:
BenCham event - Hospitality Programs at the Olympic Games
(details)
Location: Beijing
Date: 4th September

5th
CHINA: Dutch Chamber of Commerce Trip One
I am posting this on behalf of the Dutch Chinese Chamber of Commerce (DCCC). They are organizing two free business trips...

CHINA: Dalian: Annual Meeting of the New Champions 2007
This event is supposed to be the first "Davos Forum" out of Europe in Asia...

6th
CHINA: The 12th China/Wenzhou International Leather Fair
Exhibits cover all varieties of leather (synthetic leather, PU/PVC, etc.)
and machinery and chemicals...

SHANGHAI: BenCham event Shanghai - Hospitality opportunities at the Beijing Olympic Games
Hospitality opportunities at the Beijing Olympic Games. Date: Thu 6 until of September 2007...
Looking for members
Classifieds & Tips

Classifieds by Members
Could not find specific information you are looking for? Just ask! Do you have something to offer, that could be useful to others? Submit a Classified and inform others!
If your ad is no longer relevant, you are able to delete the ad yourself via “My Contributions”.

Tips by Members
Take China by storm - learn from other members about places to go, ways to travel, do's and don'ts. Also, if you have a suggestion for your fellow Club China members, be sure to add it. Every bit of information helps.
contribute a tip.
Rating systems

The Power to Get Into Contact 68%

The Contact Power indicator shows what your chances are of getting into contact with other Club China members. To increase your network potential, just try the tips below.

User Rating: 8.5/10 (180,760 votes)
Top 250: #33

Jun 26, 2007 11:34 AM
Mercaan smiled at you

May 18, 2007 05:27 AM
Luci26 smiled at you
You can also integrate google maps
Wish list

☑ Feel at home: welcome and ‘safe’
☑ Find reliable information care and research
☐ on their own level of science
☑ stage of the disease
☑ how to set up an organisation
☐ Preferable in their own language
☑ Be able to find other parents and parent groups from other countries countrymen
http://www.duchenne-community.org
New diagnosis

Posted by aimee caly on Wed (04/30/08) at 10:50 PM

My 3 year old son Liam was just recently diagnosed with DMD. We have just started on Orapred 15mg QD. I continue to see other children on other meds and supplements. Is this common and safe to do into it? He is walking and running well, and he will start wearing night splints soon. Any suggestions on how to keep them on him at night?

I am still confused on his genetic mutation. He has a duplication of 4 base pairs (TGGA) or the reverse (GTGG). Does this mean he does have a point mutation? We are still learning.

I also have 2 other boys, 5 & 2. We have not had the 2 year old tested because he is so active and completely different from Liam. Any thoughts on this? Quinn, my 5 1/2 year old, does not show any symptoms either.

Member Comments (1)

Sabrina Rizzoli wrote:

Orapred is a tradename of prednisolone.
Wish list

☑ Feel at home: welcome and “safe”
☑ Find reliable information care and research
☑ on their own level of science
☑ stage of the disease
☑ how to set up an organisation
☐ Preferable in their own language
☑ Be able to find other parents and parent groups from other countries countrymen
Under construction and for discussion

☐ Language
☐ Protected versus open
☐ Research opportunities
  - polls
  - questionnaires
  - blogs
☐ ’Dirty’ registry