



Pioneering medicine. Together.

PROGRAM

Partnerships MeetUp

2018

Utrecht, Jaarbeurs Media Plaza

Program Partnerships MeetUp 2018

Pioneering medicine. Together.

BARZONE

09:00 Walk-in and coffee

09:30 **Opening by Jorg Janssen (plenary)**

10:00 **Opportunities for Bringing Better Medical Solutions to Patients (parallel)**

MEDIA ARENA

P. 4

1. Extrapolation in Regulatory Science: Smarter use of available data

Speakers: Kit Roes, Wim Goettsch, Saskia de Wildt

AUDITORIUM

P. 6

2. Registries: Real World Challenges in Real Life Data

Speakers: Dennis van Veghel, Iris Nagtegaal, Jacqueliën Noordhoek

SHUTTLE

P. 8

3. Adapting and Reshaping Medicine for an Ageing Population

Speakers: Eline Slagboom, Paul Jansen, Sven Stegemann

BREAK OUT room 2

P. 10

4. Crossing borders: Moving Towards One Health

Speakers: Wim van der Poel, Constance Schultsz, Lucas Wiarda

BREAK OUT room 3

P. 12

5. Addressing the Needs of Poverty-Related Disease Patients: Global Partnerships with a "Dutch twist"

Speakers: Remko van Leeuwen, Danielle Roordink, Sake de Vlas, Remco de Vrueth

BARZONE

12:00 Lunch & networking

AUDITORIUM

13.30 **Keynote lecture by Tomas Salmonson (plenary)**

Tomas Salmonson is the current chair of the Committee for Medicinal Products for Human Use, CHMP, European Medicines Agency, EMA

BARZONE

14:30 Coffee break

14.50 **Essentials for Successful Collaborative Innovation (parallel)**

MEDIA ARENA

P. 14

1. Post-innovation Innovation: Platforms for Drug Repurposing

Speakers: Joris Langedijk, Adrian Freeman, Jean-Pierre Paccaud, Vincent van der Wel

BREAK OUT room 3

P. 16

2. Why, How and What you Win when you Involve Patients

Speakers: Jane Taylor, Harrie Weinans, Annemiek van Rensen

ROUND CONTROL

P. 18

3. Consortia Branding: How to Connect to Stakeholders?

Speakers: Marloes ten Kate, Bas Douma

BREAK OUT room 2

P. 20

4. Conflicting? Big Data and Privacy

Speakers: Martijn van Oijen, Birgit Wouters

AUDITORIUM

P. 22

5. Partnership Strategies towards Affordable and Accessible Healthcare

Speakers: Jon de Vlieger, Hans Büller, Irene Kanter-Schlifke, Netty Dorrestijn

AUDITORIUM

16.30 **Closing Remarks by Bert Leufkens (plenary)**

BARZONE

17:00 Networking drinks reception

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During the partnerships MeetUp we use the Networkapp. See page 24 and go to get.networkapp.eu



Register via LinkedIn or email.

Event code: PM2018

On a mission

Both Horizon Europe, the next framework program of the European Union, and the innovation policy in the Netherlands are seeing a transformation towards a mission-driven focus on societal challenges. This is fantastic news, because a mission-based approach provides direction.



With its focus on mission-based research and innovation, the relevance of this year's Partnerships MeetUp program couldn't be higher. The morning's parallel sessions focus on specific societal challenges in health, all of which depend critically on partnerships between industry, academia and society in order to develop solutions for patients.

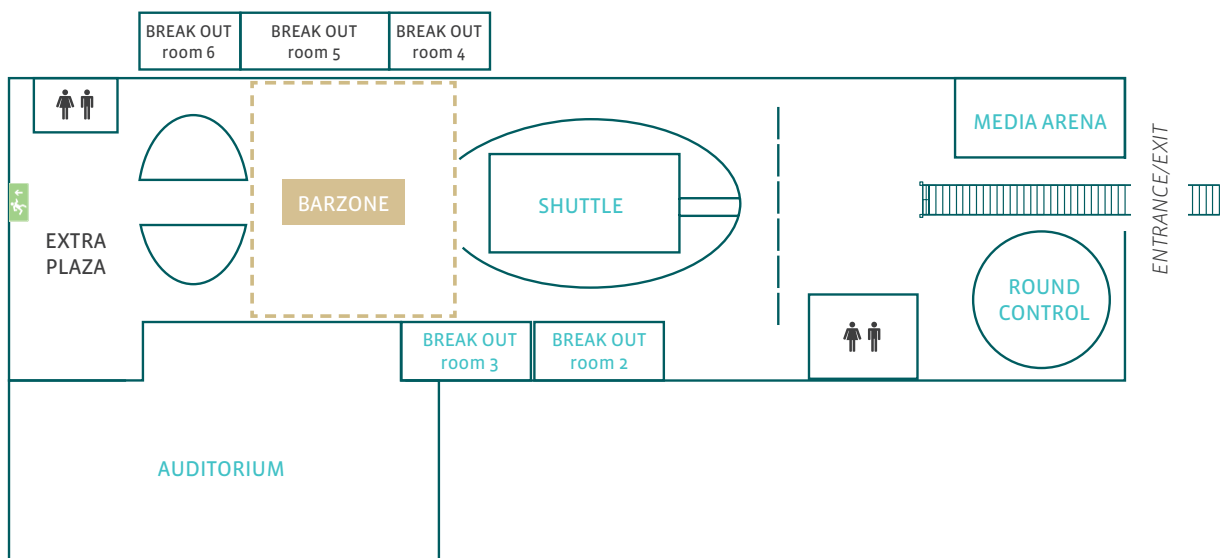
All these partnerships have more general challenges in common, whatever their specific societal challenge. In particular: how do you engage with stakeholders, involve patients, and navigate through the very polarized debate about affordability of new therapies? These are exactly the topics at hand in the afternoon parallel sessions.

At Lygature, we have been pioneering partnerships between industry, academia, and society for more than 10 years. That's because we believe partnerships are essential to solve future challenges to find medical solutions for patients: whether in data infrastructure, strategic asset sharing, regulatory innovation, or poverty related disease.

We're on a mission.

We hope you enjoy today's Partnerships MeetUp.

Jorg Janssen, Managing Director at Lygature





Session Organizers:
Anke Kip and Kevin Klein

Extrapolation in Regulatory Science: Smarter use of available data

Moderator: Bert Leufkens

Speakers

- **Kit Roes**, Professor in Clinical Trial Methodology at Julius Center, UMC Utrecht
- **Wim Goettsch**, Zorginstituut Nederland
- **Saskia de Wildt**, Paediatric Intensivist and Professor of Clinical Pharmacology at Radboud UMC, Nijmegen

With so-called precision treatments aimed at small, well-defined patient populations becoming more widely available in the coming years, new ways to generate evidence from healthcare practice are needed. This requires new extrapolation methods. Three stakeholders with different roles in the clinical development and assessment of treatments will present their perspectives on the role of extrapolation. They will tell you about how extrapolation is being used now, which challenges we face and how extrapolation can be used in the future in clinical trials, health technology assessment and clinical practice.

Professor Bert Leufkens will moderate the session and reflect on the presentations from a regulatory perspective.

Also active in regulatory science



Pieter Stolk



Jon de Vlieger

“Everyone is talking about big data and collecting more data using different techniques and in different settings, for example by using newly available wearable technology. Nevertheless, in certain patient populations we still have to draw conclusions from limited data.

In these situations, we have to develop better models with less data in order to extrapolate from smaller patient populations to broader or more diverse groups”, say program manager Anke Kip and project officer Kevin Klein.

“The question is:
do we always need more data?
Or is it sometimes enough to work
with less data, but improved
extrapolation models?”

– Anke Kip

Kevin: “The current healthcare and R&D ecosystem may not be sufficiently equipped to deal with such rapid innovation and developments anymore in ten to fifteen years from now. We need to keep thinking about how to improve our system by considering all tools for evidence generation, including extrapolation.”

At Lygature, we see the importance of including all stakeholders in such processes which aim to reshape the R&D landscape. Improving our healthcare system is not just a matter of developing new extrapolation methods, but as Anke puts it: “it is also important to consider if and how such new methods are accepted: how quickly do stakeholders adapt to new models and methods?”.

During this session, three experts will illustrate how they deal with extrapolation of data. Different perspectives on extrapolation, new methodology and acceptance of new methods will be reviewed to show the bigger picture of extrapolation in regulatory science.

Registries: real world challenges in real life data

Moderator: Rick van Nuland



Session Organizer:
Rick van Nuland

Speakers

- **Dennis van Veghel**, Netherlands Heart Registry
- **Iris Nagtegaal**, Radboudumc
- **Jacqueline Noordhoek**, Netherlands Cystic Fibrosis Foundation

Registries exist in many different forms and are set up for very different purposes. The registries landscape has become complex and fragmented, and registries often lack interoperability. However, parts of their data overlap, or could be used more effectively if combined.

This session forms a starting point in determining how to improve the registries landscape, and how to develop a harmonized way for setting up and managing registries.

Three experts share their perspectives on registries and how the data from these registries can be used in the first part of the session. In the second part, ten conditions for sustainable registries, developed by Health-RI and the Association Innovative Medicines, will be discussed in break-out sessions to determine common goals, and to establish what an implementation process for achieving these goals should look like.

Many different challenges become apparent when looking at registries. There is an administrative burden. Registries use different data standards, are set up as separate silos, and data are therefore hard to combine. “We need to develop a standardized approach so that data become FAIR: findable, accessible, interoperable, and reusable”, says program manager Rick van Nuland. “The inefficiency in processes that we have now is unacceptable, especially because we are dealing with public funding and personal data.”

Since different stakeholders are involved in using and setting up registries, all of their perspectives are necessary when arriving at a sustainable solution. “With so many different parties and interests, it is important that everyone knows what the issues are. We need to make small steps forward in tackling this problem.

This session forms the starting point”, says Rick.

“By bringing everyone together, and discussing where we want to go and how, we can make the first steps towards a strategy for improving registries in the future.”

– Rick van Nuland

Also speak to



Jan-Willem
Boiten



Tienke Schaij-
Visser



Rita Azevedo



Sjaak Peelen



Session Organizer:
Tale Slidrecht

Adapting and reshaping medicine for an ageing population

Moderator: Tale Slidrecht

The prospect of growing old is appealing to most of us, but the wish to grow old is often accompanied by the disclaimer ‘in good health’. Unfortunately, old age and good health do not always go together. Our population is ageing, and the elderly are amongst the major consumers of medicines. Our current drug development systems do not adequately consider the older patient. We therefore need to reconsider how standard practices in the development of new medical solutions can better accommodate the needs of the elderly.

In this session, three experts share their insights on ageing in healthcare and drug development, and explore possibilities for collaboration.

Speakers

- **Prof. Eline Slagboom**, chair of Leiden UMC Medical Research Profile on Ageing and of Dutch Society for Research on Ageing
- **Dr. Paul Jansen**, Expertisecentrum PHarmacotherapie bij OudeRen (Ephor), UMC Utrecht
- **Prof. Sven Stegemann**, President Geriatric Medicine Society, Professor for Patient Centric Drug Development and Manufacturing at Graz University of Technology

“Healthy aging is getting more and more attention, but not nearly enough attention as it requires,” explains program manager Tale Sliedrecht. “Older patients face a number of challenges that are not seen for younger patients: they often carry the burden of multiple chronic diseases, are physically more vulnerable, and respond differently to medicinal therapies.

“If a medicine works in a 30-year-old, it doesn’t automatically work the same in an 80-year-old.
We need to take that into consideration.”

– Tale Sliedrecht

The implications of these different factors are not addressed to their full extent in our current systems. For instance, new medical developments are often tested mainly on healthy and young people. Moreover, older patients often use a combination of different medicines, which puts them at risk for reduced safety and efficacy issues due to drug-drug interactions. Not to mention the more practical issues: breaking tablets in half can be a real struggle when you get more frail.” Everyone wants to grow old, but there is this darker side to old age that needs to be considered in our healthcare system. Something that is often easily overlooked.

Tale thinks that all stakeholders involved in the development of medical solutions need to consider this ever-growing and important target group more prominently. This is the only way to ensure that medicines are safe and effective to use, both in the young and in the old. The goal of this session is to determine where and how we can work together with different stakeholders to work towards an improved way of developing medicines, fit for an ageing population.

Also speak to



Janneke Boere



Herman Verheij



Vera Nies

**on using mobile devices
for Alzheimer patient
monitoring (RADAR-AD)**





Session Organizer:
Janneke Boere

Crossing borders: moving towards One Health

Moderator: Freek van Muiswinkel, Director External Affairs Utrecht Life Sciences;
Cluster manager Life Sciences & Health, Economic Board Utrecht

Speakers

- **Wim van der Poel**, Professor of Emerging and Zoonotic Viruses and Global One Health, Wageningen Bioveterinary Research, Department of Virology, Wageningen University and Research
- **Constance Schultz**, Professor of Global Health, Department of Global Health-AIGHD and Department of Medical Microbiology, Amsterdam UMC
- **Lucas Wiarda**, Business Unit Director and Head of the Sustainable Antibiotics Program, DSM Sinochem Pharmaceuticals

Also speak to



Wim-Jan Koot

The idea of bringing together veterinary and human medical science and healthcare, collectively called ‘One Health’, has been around for years. Now effective research on this theme is starting to be within reach, with funding potential, and public-private partnerships are taking on this joint task. However, bringing these two fields together is no small challenge: it requires engagement of academia, industry, SMEs, and government bodies. The complexity of the topic makes it essential to investigate the current status of the field, to determine an effective research strategy and to identify barriers that hold back stakeholders from collaborating. This is what three experts in One Health will discuss during this session.

“I’ve always been interested in the intersection between veterinary and human medical science. There are so many similar processes that take place in both humans and animals, not to forget in their shared environment. Yet, still we are doing research in parallel, with so much of it overlapping. I think it’s only natural to combine the two,” explains program manager Janneke Boere.

“We need to set a common goal, take responsibility, and not be afraid to take some risks in collaborations on One Health.”

“At Lygature, we see public-private partnerships as the tool to tackle the issue of One Health together.”

– Janneke Boere

Janneke: “One Health is only a small theme as part of the larger Global One Health initiative. Global One Health involves many more research fields: environmental science, agriculture, nature conservation, food safety, economics, social sciences, and many more. Let’s start with One Health first: combining the veterinary and human sectors is doable, but collaboration is key for a successful outcome.”

Lygature can provide the expertise needed to run such complex collaborations with stakeholders from different types of organizations and different fields of science.

Join us in this session to discuss how to combine veterinary and human healthcare topics in order to take a small step towards a healthier world together.





Session Organizer:
Remco de Vruh

Speakers

- **Remko van Leeuwen**, HOOKVAC Consortium, Amsterdam Institute for Global Health and Development (AIGHD)
- **Danielle Roordink**, Tuberculosis Vaccine Initiative (TBVI)
- **Sake de Vlas**, NTD Modelling Consortium, Erasmus University Medical Center
- **Remco de Vruh**, Pediatric Praziquantel Consortium, Lygature

Addressing the needs of poverty-related disease patients: global partnerships with a 'Dutch twist'

Moderator: Remco de Vruh

Also speak to



Kristina Orrling



Anke Kip



Jon de Vlieger

In the field of tropical diseases, partnerships form the basis of many initiatives. In this session, we look at the role of Dutch entities in such international partnerships. The processes involved with such partnerships, centered around collaboration and communication, have not often been discussed, and this session changes that. It shows how social innovation can help make research on tropical diseases easier and more efficient, and how partnerships in such settings can make a difference in battling poverty-related disease.

“Public-private partnerships bring the social world and the world of hardcore research together. If that is done well, developing new medicines or doing research is not that complicated.

“Everyone is working hard on our project. I often try to take a step outside to see how everything is going. Like using a thermometer.” – Remco de Vruh

It is hard, but not complicated,” says program manager Remco de Vruh. He believes Lygature can play a pivotal role in bringing these worlds together, and wants to share insights into how successful partnerships address poverty-related disease in order to help others learn from these experiences.

Successful public-private partnerships not only result in better and more efficient research

and development, but can also result in a great atmosphere. Remco: “I often feel very content and satisfied with our work. It feels great to realize that we have reached a point in some of our partnerships where the project starts to sell itself and our hard work starts to pay off.”

In this session, Remco hopes to show you what it takes to reach this state of fulfilment.





Session Organizer:
Kristina Orrling

Post-innovation innovation: platforms for drug repurposing

Moderator: Kristina Orrling

Compounds that have been found to treat a particular disease can often be used to treat other diseases as well. However, knowledge of how a compound affects the body in ways other than originally studied often doesn't reside at the company where the compound was first developed.

In this session, we want to connect the dots: how should we collaborate, what would the optimal drug repurposing platform look like, and how can we use it to stimulate drug repurposing?

Speakers and panellists

- **Joris Langedijk**, PhD - Corporate Counsel at Brabers
- **Adrian Freeman**, PhD - Emerging Innovations, AstraZeneca
- **Jean-Pierre Paccaud**, PhD - Director, Business Development and Corporate Strategy, Global Antibiotic R&D Partnership (GARDP)
- **Vincent van der Wel**, MSc - Project Leader at Fair Medicine Foundation



Session Organizer:
Tienieke Schaaïj-Visser

Why, how and what you win when you involve patients

Moderator: Tienieke Schaaïj-Visser

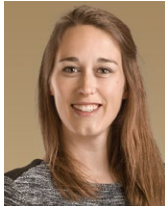
Speakers

- **Jane Taylor**, Chair of the Patient Council in the IMI-APPROACH project
- **Prof. Harrie Weinans**, principal investigator of the IMI-APPROACH project, University Medical Center Utrecht, The Netherlands
- **Annemiek van Rensen**, Senior advisor at PGOsupport

Also speak to



Irene Kanter-Schlifke



Anke Kip

Why should you involve patients in a research project? And how do you do this? What do you need to think of and organize? Involving patients is not as easy as it may sound. At Lygature we believe patient engagement is important and want to facilitate it in research projects. During this session Annemiek van Rensen from PGOsupport interviews the principal investigator Professor Harrie Weinans and the patient council chair Jane Taylor of the IMI-APPROACH project to find out how best to involve patients in research and to share lessons learned. These first-hand insights in patient engagement will be complemented with theory.

In the second half of the session, round-table discussions allow for participants to determine when and how to involve patients by discussing case studies.

Patient engagement is important in research projects, not only because funders, patient organisations, and governments ask for it, but most importantly because it can enrich science and increase ultimate impact. That's easier said than done, however, explains program manager Tienke Schaaïj-Visser: "There are, for example, many tools available, but which one should you use when? Also, most tools are developed for single timepoint interactions, and not for the full scope and term of a project. At Lygature, we aim to support consortia in a systematic way. We help them to determine the right moments and methods to engage patients throughout the entire research project. With that, we hope to make it easier, and to take away possible perceived barriers."

"The best thing about patient engagement? When you realize that one and one has become three."

– Tienke Schaaïj-Visser

Tienke discusses how research projects benefit from patient engagement: "Sometimes dialogue with patients gives you something small, like motivation for the researcher, or a patient who feels heard. But patient engagement can bring much more. Patients have ideas about how research should be done, what should be investigated, and how to get results that will actually be used in healthcare.

I think involving this group, or any group of stakeholders, is the only way in which you can really reach the results you're aiming for. You can compare it to a company that asks customers what a product should look like in market research; I think patient engagement is that, and more."



Consortia branding: how to connect to stakeholders

Moderator: Alexander Duyndam



Speakers

- **Marloes ten Kate**, presenter, program maker and science journalist (www.marloestenkate.nl)
- **Bas Douma** from Bascommunicatie (www.bascommunicatie.com)

Also talk to



Session Organizers:

Alexander Duyndam and Elize Brolsma



Leonie
Hussaarts



Kristina Orrling

Many research consortia are temporary in nature, and yet to have impact they need to be properly defined and recognizable. Manager Communications and External Affairs Alexander Duyndam believes this requires them to develop a brand identity. This session shows what research consortia can learn from marketing: how can you give something as complex as a research consortium meaning and how do you make it recognizable? Three experts in marketing and science communications will present their ideas on how best to approach the branding of research consortia. Following the presentations, we will discuss these issues interactively. You will leave this workshop with concrete tips that you can implement immediately.

“Researchers often find it hard to believe that emotion plays such a big role in communicating science. They are part of a strange mix of science, precision, and analysis on the one hand, and of feelings, warmth, involvement, and core values on the other,” says Alexander.

In this session, he hopes to integrate these two

worlds, which may seem to be such an unlikely combination: “In our ‘attention economy’ you will need a podium to be successful. Branding and communication can provide this podium.”

“I want to show that
communication involves
everybody within an organisation.”
– Alexander Duyndam

Alexander explains how people often get stranded in a discussion of which communication tools to use. “As a communication professional I try to take a step back and look first at the situation more strategically: what do you want to accomplish and who do you want to reach? Only then can we determine which tools to use. We need to go from just sending information to a meaningful interaction

with the outside world.” Lygature can help you with this process by developing a brand identity for research consortia and taking care of all project communications during its runtime.



Session Organizer:
Sjaak Peelen

Conflicting? Big data and privacy

Moderator: Nico van Meeteren, Health~Holland

Most of us can see the value of bringing different datasets together to improve healthcare research. But what are the consequences of this trend with regards to privacy? In this session we look at the trends and goals of combining datasets, and their consequences for privacy.

Discuss with us what we should or shouldn't want – and see if your viewpoint changes during the session.

Speakers

- **Martijn van Oijen**, Amsterdam UMC, locatie AMC
- **Birgit Wouters**, Maastricht University



Calls for project proposals ask researchers to think about privacy more in recent years, and clinical studies are checked by an ethical commission that reviews privacy. However, this is only part of the story. Program manager Sjaak Peelen describes how just thinking about privacy within your research project in general is not enough: “Once you’re actually working with these data, you also have to consider more mundane things like transportation or where the data are stored. This is not something that can be found in a protocol.”

“These aren’t data on mice. We’re talking about patient data here, with all the sensitivities and potential privacy issues that come with it.”

– Sjaak Peelen

An example from Sjaak shows just how unexpected privacy issues can be: “When you consider MRI images, people can sometimes be identified based on the shape of their ears. Even though a researcher is not interested in this part of the head, and will not pay much attention to it, this is a privacy issue that needs to be considered. Should we crop the ears from the images? How do you deal with this?” This example shows that privacy can involve simple things that are easily overlooked.

Operational and often overlooked privacy issues relating to transporting data and recognizability on MRI images need consideration. However there is also a bigger issue at hand. Alongside the trend towards more sharing and integration of clinical, biomedical, epidemiological and patient-generated data, with its aim of improving healthcare, we see a flipside. Even though data are de-identified, combining them leads to an increased risk of compromising the privacy of patients. This session aims to discuss these privacy issues and how we can all deal with them together.

Also speak to



Serena ter Kuile



Jan-Willem Boiten



Rita Azevedo



Tienek Schaaïj-Visser





Session Organizer:
Jorg Janssen

Partnership strategies towards affordable and accessible healthcare

Moderator: Michel Rudolphie, Board member at Lygature and former director of the Dutch Cancer Society

Speakers

- European Lead Factory: **Jon de Vlieger**, Business Development Director at Lygature
- FAIR medicine: **Hans Büller**, founder
- Oncode Institute: **Irene Kanter-Schlifke**, Program Manager Oncode at Lygature
- Utrecht Center for Affordable Biotherapeutics: **Netty Dorrestijn**, General Manager

Also speak to



Irene Kanter-Schlifke



Remco de Vrueth



Jon de Vlieger

Healthcare costs are increasing. Somehow, the discussion focuses on just one small part of the total budget: medicines. With intense debate, different parties end up blaming each other, rather than trying to work together. On the bright side, even within this polarized playing field, there are examples of partnerships that do work. This session illustrates why and how public-private partnerships can pave the way to finding a solution to this important societal issue.

Four partnerships will pitch their way of working together, with the aim of reducing the costs of drug discovery, development and/or production.

One key problem is that people underestimate the complexity of drug development.

A couple of years ago, the founders of a successful Dutch biotech company framed it effectively: “There is a very naive thought in the Netherlands: you have a doctor with a good idea who starts a company and you call that innovation. But you cannot just put together a Boeing 747 in your backyard.” Luckily, people realize more and more that innovation in medicine cannot be achieved by one single party anymore, because it requires collaboration between academia, industry, and society.

“No single party, not society,
not the government, nor industry,
can tackle this problem alone.

We need collaboration.”

– Jorg Janssen

Drug development takes time and money, and at Lygature we often see the extent to which it is an undertaking that cannot be managed alone. Utilizing the strength of public-private partnerships includes placing an emphasis on transparency in costs.

This session serves as a podium to show how public-private partnerships can successfully contribute to affordable and accessible healthcare by using new models to develop new medicines.



Contact us

If you have any questions regarding the Partnerships MeetUp.

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