

# A short history of the first 3 years of the Community Genetics Network and its newsletter

Leo P. ten Kate · Annie Plourde

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**Abstract** When in 2007 it became clear that the Karger journal *Community Genetics* would change its name and scope, the first author started to establish an international, multidisciplinary e-mail network and a newsletter with papers authored by the members of the network. This paper reports on the first 3 years of the network. At the end of the 3-year period, there were 858 members, 50 newsletters had appeared, and almost 1,500 different papers from 458 journals had been cited. This model may serve as an example for others who want to bring together those sharing a common interest.

## Introduction

When, in 2007, it became clear that the journal *Community Genetics* (Karger) would change its name and focus to *Public Health Genomics* (Ten Kate 2008a, b; Karger 2008), the question arose whether this would be the end of community genetics as a separate field of science and practice. Would community genetics disappear from our vocabulary, or would its concept and name be able to attract a sufficient number of “followers” for a viable continued existence?

To obtain an indication of the answer to this question, it was decided (by LtK) to assemble individual researchers and others into an e-mail network with a regular newsletter containing references to recent publications and messages

from and for its members, as well as information on upcoming meetings relevant to the field. To ensure enduring engagement of the members in the network, the newsletter should only be available to them and not be publicly accessible. Membership should however be free of charge.

The 50th newsletter of the network appeared on August 1, 2010 and was sent to 858 members in 70 countries. In this paper we describe the growth and origin of the membership, and the growth and origin of the references to papers published by the members of the network and listed in the newsletter. The main topics of the listed papers are also reported.

## Members

Members were recruited one by one by e-mail. Attached to the invitation was a description of the aim of the network and its service to the members (see Box 1), and a specimen of the most recent newsletter. Recruitment started in May 2007 by inviting persons known to be interested in community genetics, followed by inviting corresponding authors of previous papers published in the journal *Community Genetics*, as their e-mail addresses were publicly available on their printed papers. As a next step, a number of relevant journals were screened regularly for papers on subjects within the scope of community genetics, and their corresponding authors were subsequently invited to become a member. After a while, this approach was replaced by weekly PubCrawler searches in PubMed and GenBank on items within the scope of community genetics, such as genetic screening, genetic education, genetics in primary care, and so on (see <http://pubcrawler.gen.tcd.ie/>). From the weekly lists of references, authors of papers within the community genetics domain were invited when an e-mail address could be found.

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L. P. ten Kate (✉)  
Department of Clinical Genetics, VU University Medical Center,  
Amsterdam, The Netherlands  
e-mail: lp.tenkate@vumc.nl

A. Plourde  
Ecogene-21, Centre affilié universitaire régional de Chicoutimi  
(CSSS de Chicoutimi),  
Chicoutimi, QC, Canada

**Table 1** Specimen of the original attachment accompanying invitations to become a member

### The International Multidisciplinary Community Genetics Network

**Community Genetics** (including community genomics) is defined as the art and science of the responsible and realistic application of genetics and genomics at the level of populations and their subgroups, to the benefit of as many individual persons as possible. Areas of particular interest are genetic screening, genetic education, access and quality of genetic services and preconception care, genetics in primary care, genetic registries, genetics for disadvantaged populations, public consultation and epidemiologic, economic, psychosocial, ethical and legal issues

The **aim** of the international multidisciplinary community genetics network is to facilitate communication between those working in the field of community genetics and genomics.

**Members** of the network are all those who have expressed the wish to become a member. Just send an e-mail to [commgennet@gmail.com](mailto:commgennet@gmail.com)

Members receive a monthly **newsletter** by e-mail and are invited to send information to the editor of the newsletter pertaining to **upcoming events**, such as workshops, conferences etcetera. The announcements of these events will be published in the monthly newsletter.

Members are also invited to keep the editor informed on **references** (Vancouver style) of their own scientific publications with relevance to community genetics and genomics, of which they are one of the authors, which have appeared recently (not more than 3 months ago) in a peer reviewed journal and are listed in PubMed. These references will be published in the monthly newsletter as a service to the other members.

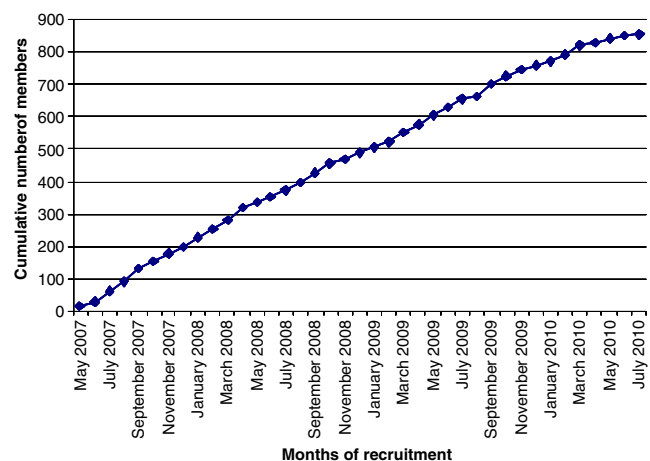
Members may also send **queries** to all other members for instance to find out who has experience with a particular community genetics service. They are also welcome to **announce positions** open for job application.

The definition of community genetics shown here is replaced presently by a more recent definition (Ten Kate et al. 2010). Present definition: Community genetics is the art and science of responsible and realistic applications of health and disease-related genetics and genomics knowledge and technology in human populations and communities to the benefit of individuals therein. Community genetics is multi-, inter-, and transdisciplinary and aims to maximize benefits while minimizing the risk of harm, respecting the autonomy of individuals and ensuring equity

Between May 2007 and July 2010, 1,388 first invitations were sent, out of which 8% were undeliverable, leading to 395 (31%) positive answers and a few expressing regret. The great majority of the nonresponders (811) were approached a second time, generally 1 month after the first invitation. Another 207 people accepted (26% after subtracting 0.7% undeliverable mails). In this way a total of 602 members were recruited by personal invitation. Another 256 members were the result of spontaneous requests by people who had heard from others about the newsletter and by suggestions of members to include other people of their team.

Over the first 3 years of the network, the number of members increased gradually with a constant flow (Fig. 1). Monthly, an average of 22 ( $\pm 8$ ; range 4–41) members joined the network. Members originated from 70 countries, mainly from (North) America and Europe (Table 1). Half of the members came from three countries (USA, UK, and The Netherlands). The disproportionate high number of members for The Netherlands (85)—a country with only 16 million inhabitants—is explained by the existence since

2001 of a national association for community genetics and public health genomics. Low and middle-income countries are, not unexpectedly, underrepresented: fewer resources,



**Fig. 1** Evolution of membership of the Community Genetics Network. Recruitment started 3 months before publication of the first issue of the newsletter

**Table 2** Number of members by continent and country, August 2010 (countries with less than five members are grouped together)

Continent	Country	Number	Continent	Country	Number
America		329	Asia		115
	USA	237		India	21
	Canada	68		Israel	19
	Brazil	15		Iran	9
	5 other countries	9		Saudi Arabia	6
Europe		329	Turkey	6	
	UK	103	Japan	5	
	Netherlands	85	Lebanon	5	
	Italy	23	Pakistan	5	
	Belgium	13	17 other countries	39	
	France	13	Australia/Pacific	65	
	Germany	12	Australia	61	
	Greece	11	1 other country	4	
	Norway	7	Africa		20
	Portugal	7		South Africa	8
	Spain	7		7 other countries	12
	Sweden	7			
	Denmark	6			
	15 other countries	35			

fewer researchers, fewer publications, and less visibility of those qualifying for membership.

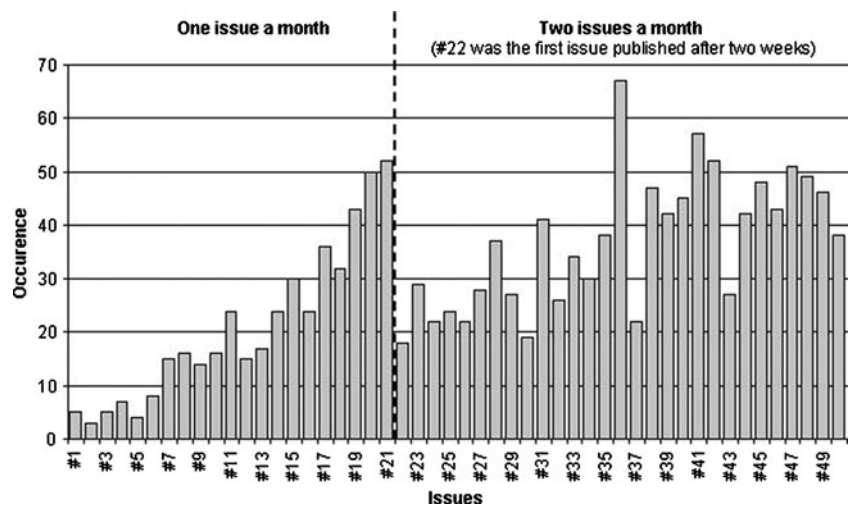
**References to papers by members**

Members were invited, originally, to send references to their recent papers (less than 3 months old), in the community genetics domain, written in the English language, and listed in PubMed, to the then coordinator (LtK) of the network who included them with a hyperlink to PubMed in the upcoming newsletter. Clinical case reports were excluded from the beginning. Soon it became

apparent that members were slow in reporting their papers. So, within a year, the ascertainment of references to papers of the members was done by a weekly search through PubMed on author’s name (family name and first initial). As different authors may have the same family name and first initial, the weekly results have to be checked by comparing the information on first name and affiliation in the paper and the network database.

The number of references listed in the newsletter increased gradually (Fig. 2). Originally, the newsletter was published once a month, but given the continuous increase in the number of references, it was decided to publish the newsletter twice a month from issue 22, May 2009, onward (with the exception

**Fig. 2** Number of cited references per issue of the newsletter of the Community Genetics Network. A total of 1,489 different papers were cited over 3 years. Twenty two were cited in more than one issue (duplicates, leading to 1,511 citations)



**Table 3** Distribution of number of papers of members by journal in which they were published (excluding the top 10 journals listed in Table 4)

Number of papers by journal	Journals		Papers	
	Number	Percentage <sup>a</sup>	Number	Percentage <sup>b</sup>
1	278	57.3	278	18.4
2	82	16.9	164	10.9
3	47	9.7	141	9.3
4	19	3.9	76	5.0
5	13	2.7	65	4.3
6	4	0.8	24	1.6
7	9	1.9	63	4.2
8	6	1.2	48	3.2
9	4	0.8	36	2.4
10	1	0.2	10	0.7
11	3	0.6	33	2.2
12	1	0.2	12	0.8
13	3	0.6	39	2.6
14	2	0.4	28	1.9
15	1	0.2	15	1.0
17	2	0.4	34	2.3
Total	475	97.9	1,066	70.5

<sup>a</sup>Percentage of all journals (including top 10)

<sup>b</sup>Percentage of papers in all journals (including top 10)

of the yearly holiday season). After 3 years, the number of cited references exceeded 90 papers a month. The increase in monthly number of references parallels the monthly increase in members. The way the references were selected does not allow speculating on an eventual increase in the number of papers published within the field of community genetics.

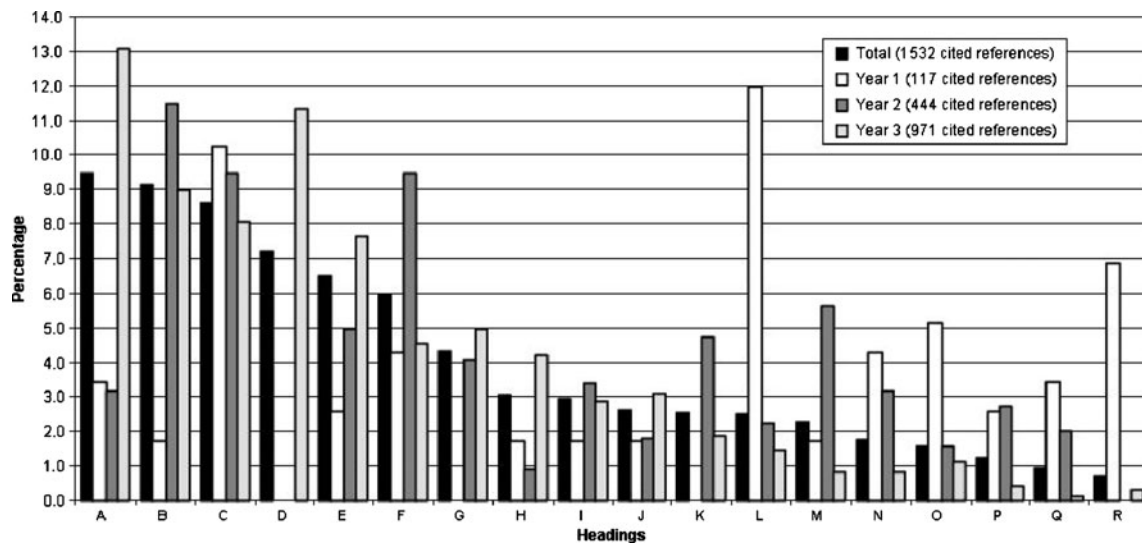
Including the 50th newsletter, references to a total of 1,489 papers by members were recorded. These 1,489 papers were published in a wide range of journals, 485 in total (Tables 2 and 3). A total of 278 (57.3%) journals contained only one paper, 82 (16.9%) revealed two papers, 47 (9.7%) three papers, and so on. The top 10 journals (Table 3), representing 2.1% of all journals with papers from our members, contained 445 (29.5%) of all the papers

cited. The contribution of the journal *Community Genetics* (Karger) was restricted to the first period of the newsletter. For the second period (issues 26–50), *Nature Genetics* with 16 papers would have taken the empty place in a top 10 restricted to this period. There were already nine references to papers published in the *Journal of Community Genetics* (Springer; first issue appearing March 2010).

The topics of the papers covered a wide range of subjects. References to papers on a related subject were therefore clustered in each newsletter under one of the 71 headings used during that period, such as “genetic screening” or “psychosocial issues,” enabling readers to focus on papers of their interest. The 10 headings with the largest number of references for each year led to a

**Table 4** Top 10 journals with papers of network members

Name of journal	Number papers			
	Issues 1 to 25	Issues 26–50	Total	% total
<i>Genetics in Medicine</i>	34	38	72	4.8
<i>Journal of Genetic Counseling</i>	37	28	65	4.3
<i>Genetic Testing and Molecular Biomarkers</i>	37	25	62	4.1
<i>European Journal of Human Genetics</i>	24	28	52	3.4
<i>Public Health Genomics</i>	16	35	51	3.4
<i>American Journal of Medical Genetics A</i>	22	18	40	2.6
<i>Prenatal Diagnosis</i>	15	16	31	2.1
<i>Clinical Genetics</i>	8	20	28	1.9
<i>Community Genetics</i>	23	–	23	1.5
<i>Familial Cancer</i>	8	13	21	1.4
Total	224	221	445	29.5



**Fig. 3** Frequency distribution of papers by heading and year of publication of the newsletter (restricted to the 10 headings with the largest number of references in each year). Percentage was calculated on the total number of cited references for each year (white, dark gray and light gray bars) or in total (black bars). Explanation of symbols: A Genetic disorders, B Specific disorders or mutations in specific

communities, C Genetic screening, D Complex conditions, E Congenital disorders, F Prenatal screening and testing, G Genetic testing, H Miscellaneous, I Family history, J Population history, K Genetic counseling, L Genetics education and literacy, M Psychological issues in hereditary cancer, N Patient perspective, O Bio-banks, P Testing minor, Q Genetic services, R Susceptibility genes and testing

list of 18 headings, comprising 73% of all the papers (Fig. 3). These headings listed 74 (63%), 314 (71%), and 734 (76%) of the papers in the first, second, and third year, respectively. There is a remarkable increase in papers placed under the headings “genetic disorders” (A), “specific disorders or mutations in specific communities” (B), and “complex disorders” (D), while the heading “genetics education and literacy” (L) lost its leading position after the first year.

**Discussion**

The original question whether community genetics’ concept and name would be able to attract a sufficient number of “followers” for a viable continued existence can be answered positively, at least when a so-named service is offered free of charge. The recruitment of members and the production of the newsletter were done by the first author who is officially retired. Since November 2009 preparation and sending of the newsletter are transferred to the second author who is on the pay list of the ECOGENE-21 project at Chicoutimi, Canada. At the time of submission of the revised version of this paper, the number of members is 939 in 73 countries. The e-mail address commgenet@gmail.com is still valid for readers who want to contact us.

Apart from the establishment of the Community Genetics Network and its newsletter, three more relevant developments took place. In 2010, the first issues of the

*Journal of Community Genetics* appeared (Schmidtke and Ten Kate 2010), published by Springer; there was a consensus definition of “community genetics” published (Ten Kate et al. 2010), and the ECOGENE-21 team took steps to establish an International Society of Community Genetics and Genomics.

Finally, this case report shows that it is not too difficult to establish an international multidisciplinary e-mail network and a regular newsletter based on scientific and other output if its members. Our model may serve as an example for others who want to bring together those sharing a common interest.

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