part in the pathogenesis of RA.

F. TAKEUCHI, *MD, Asst. Prof.*[1]
K. KAWASUGI, *MD*[1]
H. NABETA[1]
M. MORI, *MD*[1]
M. MORITANI, *PhD*[2]
M. GOTO, *MD*[3]
K. MATSUTA, *MD*[4]
A. YAMADA, *MD*[5]
T. CHIHARA, *MD*[6]
T. HANYU, *MD, Asso. Prof.*[7]
T. MURAYAMA, *MD*[8]
S. YAMAMOTO, *MD*[9]
N. MURATA, *MD*[10]
T. MATSUBARA, *MD*[11]
M. ITAKURA *MD, Professor*[2,12]

[1]Dept. of Internal Medicine, Faculty of Medicine, University of Tokyo, Tokyo; [2]Otsuka Dept. of Molecular Nutrition, School of Medicine, the University of Tokushima, Tokushima; [3]Dept. of Rheumatology, Tokyo Metropolitan Otsuka Hospital, Tokyo; [4]Matsuta Clinic, Tokyo; [5]Dept. of Medicine, Sagamihara National Hospital, Sagamihara; [6]Chihara Clinic, Ichikawa; [7]Dept. of Orthopedic Surgery, Niigata University School of Medicine; [8]Kanazawa Rehabilitation Hospital, Kanazawa; [9]The Center for Rheumatic Disease, Matsuyama Red Cross Hospital, Matsuyama; [10]Dept. of Orthopedic Surgery, Osaka-minami National Hospital, Kawachinagano; [11]Matsubara Clinic, Kobe; [12]Institute for Genome Research, the University of Tokushima, Tokushima, Japan. Please address correspondence and reprint requests to: Fujio Takeuchi M.D., #504 Lab, Department of Internal Medicine, Faculty of Medicine, University of Tokyo, 7-3-1 Hongo, Bunkyo-ku, Tokyo 113-8655, Japan. E-mail: fujio-tky@umin.ac.jp

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Acknowledgements and Affiliations
This study was supported by grants from the Ministry of Education, Science and Culture of Japan, and from Manabe Foundation. The authors gratefully acknowledge the kind support of Nobuo Takubo MD in Matsuyama Red Cross Hospital, Masuo Saito MD in Saito Clinic, Koji Goto MD in Goto Clinic, Tatsuo Morisada MD in Morisada Clinic, Keiko Ishihara MD, Kenji Takizawa MD, and Kiyoaki Tanimoto MD in Tokyo University.

Results of a multi-national survey regarding a feasibility study for a therapeutic trial in juvenile systemic sclerosis

Sir,

Juvenile systemic sclerosis (jSSc) is a very rare disease (1). Although it has been shown (2) that survival, morbidity and mortality differ between pediatric and adult populations, current therapeutic approaches demand that pediatric rheumatologists apply experience gained from adults, although only few prospective and controlled studies exist.

In order to evaluate the feasibility of a comparative two-branch therapeutic study entailing the recruitment of patients with disease courses shorter than 18 months, a survey of all members of the Pediatric Rheumatology International Trials Organization (PRINTO), a European collaborative study group with members in 16 countries, was carried out in February 1999. In April the survey questionnaires were sent to members of the Pediatric Rheumatology Section of the American Academy of Pediatrics (AAP).

The response within the PRINTO group was 27% and in the AAP group 23%. Survey results are shown in Table I. Forty-three new patients with jSSc are seen each year in the centers interested in participating in the study. This means that it should be possible to recruit a sufficient number of patients for a multi-center study with two branches. This could represent an important step forward in our attempt to learn more about the effective treatments of patients with juvenile systemic sclerosis.

I. FOELDVARI, *MD*
Pediatric Rheumatology Unit, University Children's Hospital, 20246 Hamburg, Germany.

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Table I. Results of a survey of pediatric rheumatologists in Europe and America.

	Pediatric Rheumatology International Trial Organization Members mailing list	American Academy of Pediatrics/Pediatric Rheumatology Section mailing list
Number of members on the mailing list	171	133
Number of questionnaires returned because of wrong address	4	3
Number of negative responses (not interested in participating)	8 (5%)	5 (4%)
Number of positive responses (interested in participating)	38 (22.2%)	25 (19%)
Number of patients followed in centers interested in participating	92 (2.4/center)	60 (2.4/center)
Number of newly diagnosed patients/year in the centers interested in participating	25 (0.7/center)	18 (0.7/center)