

Rank	Code	Title	Area	Institution	MINISTRY FINAL BUDGET	Total fund	Ministry Request fund	Confinancing fund	Eval Average
1	RF-FVG-2008-1203207	Clinical history and long-term cost-effectiveness of Enzyme Replacement Therapy (ERT) for Gaucher Disease in Italy	Malattie rare Area C	Friuli-Venezia Giulia	250.000,00	1.135.300,00	503.500,00	39000	83,33
2	RF-INT-2008-1241451	Rare Cancers in Italy: surveillance and evaluation of the access to diagnosis and treatment	Malattie rare Area C	ISTITUTO TUMORI MILANO	250.000,00	554.804,00	382.250,00	0	81,33
3	RF-VEN-2008-1201767	Primary Ciliary Dyskinesia (PCD): diagnosis, clinical phenotypes and prevalence in an Italian pediatric population.	Malattie rare Area C	Veneto	250.000,00	748.600,00	347.000,00	13000	79,67
4	RF-IMG-2008-1282140	Porphyrias: biochemical and genetical quality controls. Unusual signs and symptoms: hair shaft alterations	Malattie rare Area C	SAN GALLICANO	250.000,00	497.000,00	314.000,00	0	77,33
5	RF-LOM-2008-1249670	DIAGNOSTIC AND THERAPEUTIC WORK - UP FOR PREVENTING AORTIC ANEURYSM DISSECTION IN HERITABLE COLLAGEN DISEASES	Malattie rare Area C	Lombardia		675.000,00	361.500,00	284700	76,33
6	RF-MAU-2008-1199688	Clinical Follow-up of individuals with alpha-1 antitrypsin deficiency identified through a population screening in Val Trompia	Malattie rare Area C	MAUGERI		465.000,00	340.000,00	0	73,33
7	RF-IGG-2008-1203866	NATIONAL COLLABORATIVE GLYCOGEN STORAGE DISEASE TYPE I REGISTRY	Malattie rare Area C	GASLINI		413.200,00	138.000,00	15000	72,67
8	RF-PIE-2008-1219210	ACTH TEST IN THE DIAGNOSIS OF PRE-CLINICAL PRIMARY HYPOADRENALISM IN PATIENTS WITH AUTOIMMUNE DISEASES	Malattie rare Area C	Piemonte		200.000,00	200.000,00	0	71,67
9	RF-IMG-2008-1291293	Systemic sclerosis and diesel engine exhaust nanoparticles : in vitro and in vivo assessment of the pro-inflammatory and pro-fibrotic potential of airborne particulate in a model of immune-mediated disease	Malattie rare Area C	SAN GALLICANO		1.314.000,00	334.000,00	0	71,33

BANDO MALATTIE RARE - AREA C

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10	RF-OMM-2008-1263736	Familial Mediterranean Fever in Italy	Malattie rare Area C	MAGGIORE		156.400,00	143.400,00	13000	71
11	RF-LOM-2008-1260862	GENS ITALY: MULTIREGIONAL REGISTRY FOR RARE DISEASES ASSOCIATED WITH STROKE	Malattie rare Area C	Lombardia		1.001.000,00	800.000,00	0	70,67
12	RF-OOB-2008-1297064	Rare disease and cancer risk: a population study in Apulia region	Malattie rare Area C	ONCOLOGICO DI BARI		327.000,00	200.000,00	127000	69,67
13	RF-INN-2008-1199204	Improving the quality of care delivery in patients with inherited chronic progressive spinocerebellar ataxias by the development of a remote web-based program for long-term follow-up	Malattie rare Area C	CARLO BESTA		561.600,00	498.000,00	0	69,33
14	RF-TOS-2008-1229944	Screening for Autoimmune Polyglandular Syndrome Type 2 in patients with autoimmune thyroiditis: definition of methodology and cost-benefit analysis	Malattie rare Area C	Toscana		266.000,00	217.000,00	0	69,33
15	RF-INM-2008-1240131	NEWCARER: creation of a network for Aicardi Goutieres Syndrome supported by an advanced IT system: a model for improving knowledge of prevalence, diagnosis, research and care in a rare disease	Malattie rare Area C	MONDINO		430.000,00	369.000,00	0	69,33
16	RF-LOM-2008-1259348	DIAGNOSTICS AND THERAPEUTIC APPROACHES TO RARE DYSLIPIDEMIAS FROM GPS TO SPECIALISED CENTERS	Malattie rare Area C	Lombardia		525.800,00	272.800,00	0	65,67
17	RF-INN-2008-1259954	CLINICAL AND MOLECULAR CHARACTERIZATION OF A LARGE ITALIAN POPULATION AFFECTED BY MYOTONIC DYSTROPHY TYPE 1 (DM 1) IN VIEW OF A NATIONAL REGISTRY OF THE DISEASE	Malattie rare Area C	CARLO BESTA		689.100,00	525.660,00	0	65

BANDO MALATTIE RARE - AREA C

Rank	Code	Title	Area	Institution	MINISTRY FINAL BUDGET	Total fund	Ministry Request fund	Confinancing fund	Eval Average
18	RF-PIE-2008-1276711	Italian collaborative multidisciplinary network on long term home ventilated children	Malattie rare Area C	Piemonte		0,00	0,00	0	64,33
19	RF-null-2008-1221469	RARE DISEASE AS CAUSES OF NEONATAL EPILEPTIC ENCEPHALOPATHY	Malattie rare Area C	Emilia-Romagna		210.000,00	180.000,00	10000	64
20	RF-FCG-2008-1206238	Development and validation of quality of life disease-specific outcome measures for two rare diseases: Charcot Marie Tooth disease and Facioscapulohumeral Distrophy.	Malattie rare Area C	DON GNOCCHI		241.000,00	169.500,00	0	63,33
21	RF-OMM-2008-1254702	SET UP OF A NATIONAL COLLABORATIVE NETWORK FOR THE CARE OF TYPE I SPINAL MUSCULAR ATROPHY (SMA1)	Malattie rare Area C	MAGGIORE		683.500,00	400.000,00	30000	63
22	RF-LOM-2008-1271606	THE EUROPEAN GUIDELINES FOR THE MANAGEMENT OF AMYOTROPHIC LATERAL SCLEROSIS: APPLICATION AND SATISFACTION IN A POPULATION-BASED SAMPLE	Malattie rare Area C	Lombardia		274.875,00	205.800,00	0	62,33
23	RF-INT-2008-1240858	Evaluation of genetic counselling in the management in Hereditary Colorectal Tumours Syndromes (FAP HNPCC): diagnostic, therapeutic approach and psychological issue	Malattie rare Area C	ISTITUTO TUMORI MILANO		530.770,00	409.767,00	0	60
24	RF-INN-2008-1245123	Psychiatric and behavioural disturbances in Huntington's disease patients: the most important cause of functional disability and caregivers' burden. Survey and possible therapeutic measures	Malattie rare Area C	CARLO BESTA		323.792,00	242.032,00	0	60

BANDO MALATTIE RARE - AREA C

Rank	Code	Title	Area	Institution	MINISTRY FINAL BUDGET	Total fund	Ministry Request fund	Confinancing fund	Eval Average
25	RF-IMG-2008-1282142	Hereditary haemochromatosis HFE correlated: retrospective-prospective-genetic-clinical-anatomopathological study - identification of new predictive biomarkers	Malattie rare Area C	SAN GALLICANO		1.792.000,00	565.000,00	0	58,67
26	RF-ISS-2008-1257517	Validation and use of an augmentative communication instrument for measuring subjective quality of life among individuals with rare diseases.	Malattie rare Area C	Istituto Superiore di Sanita'		247.000,00	127.000,00	0	58,33
27	RF-PUG-2008-1281469	A NEW TOOL TO ASSESS HEALTH RELATED QUALITY OF LIFE IN PAEDIATRIC PATIENTS WITH RARE DISEASES INTEGRATED IN THE HEALTH TECHNOLOGY ASSESSMENT PROCESS (HRQOL)	Malattie rare Area C	Puglia		463.370,00	367.770,00	50000	58,33
28	RF-IDI-2008-1233589	Unmet needs, quality of life and family burden among ichthyosis patients	Malattie rare Area C	ISTITUTO DERMOPATICO IMMACOLATO		345.890,00	213.290,00	0	58
29	RF-EMR-2008-1216039	ESTABLISHMENT OF A MULTIDISCIPLINARY PROSPECTIVE STUDY OF CONGENITAL RARE PATHOLOGIES AFFECTING THE LOCOMOTOR SYSTEM FOCUSING ON THE UPPER EXTREMITY BASED ON: EPIDEMIOLOGY AND GENETICS, DIAGNOSTIC PROTOCOLS, TREATMENT AND QUALITY OF LIFE IN RELATIONSHIP TO THE BIOPSYCHOSOCIAL ICF MODEL	Malattie rare Area C	Emilia-Romagna		645.000,00	400.000,00	0	56,67
30	RF-EMR-2008-1221817	INCIDENCE OF DENTAL PATHOLOGIES AND PREVENTION STRATEGY IN MENTAL RETARDATION FROM RARE PATHOLOGY	Malattie rare Area C	Emilia-Romagna		397.000,00	313.000,00	0	55,33

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31	RF-ISS-2008-1236355	Diagnosis and management of favism and haemolytic anaemia syndromes related to glucose-6-phosphate dehydrogenase deficiency	Malattie rare Area C	Istituto Superiore di Sanita'		416.500,00	416.500,00	0	55,33
32	RF-IOR-2008-1260722	HUB & SPOKE NETWORK FOR SKELETAL DYSPLASIA: AN INTERDISCIPLINARY APPROACH TO OPTIMIZE THE ORGANIZATION OF CLINICAL-DIAGNOSTIC TRAILS/ GUIDELINES FOR A BETTER PATIENTS QUALITY OF LIFE.	Malattie rare Area C	RIZZOLI		480.000,00	340.000,00	0	54
33	RF-IEM-2008-1276420	CLASSIFICATION OF FUNCTIONING DISABILITY AND HEALTH, CHILDREN AND YOUTH ADAPTATION (ICF-CY), AS A FRAMEWORK TO READ DISABILITY AND SERVICE PROVISION IN RELATION TO THE PERCEIVED QUALITY OF LIFE IN CHILDREN WITH RARE NEUROLOGICAL DISEASES	Malattie rare Area C	MEDEA		1.173.700,00	457.700,00	21000	53,67
34	RF-ICH-2008-1287951	The hidden face of copper in Italy: the epidemiology and epigenetics of Wilson disease	Malattie rare Area C	HUMANITAS		422.700,00	422.700,00	0	53,67
35	RF-PUG-2008-1270179	THE IMPACT OF THE EPIDERMOLYSIS BULLOSA DISEASE ON THE PSYCHOLOGICAL WELLNESS AND ON THE LIFE QUALITY OF PATIENTS AND CAREGIVERS. CARE AND TREATMENT	Malattie rare Area C	Puglia		540.000,00	300.000,00	50000	52,67
36	RF-SIC-2008-1208176	STUDY ON PREVALENCE OF PULMONARY ARTERIAL HYPERTENSION IN AUTOIMMUNE RHEUMATIC DISEASES PATIENTS FROM EASTERN SICILY AND ORGANIZATION OF DIAGNOSTIC AND MEDICAL CARE SHARED COURSES	Malattie rare Area C	Sicilia		220.000,00	185.000,00	35000	52

BANDO MALATTIE RARE - AREA C

Rank	Code	Title	Area	Institution	MINISTRY FINAL BUDGET	Total fund	Ministry Request fund	Confinancing fund	Eval Average
37	RF-MAU-2008-1204576	Integrated home care for Amyotrophic Lateral Sclerosis patients	Malattie rare Area C	MAUGERI		830.000,00	600.000,00	0	49
38	RF-ISS-2008-1235151	Estimation of epidemiological indicators, evaluation of clinical-diagnostic pathways and Health Related Quality of Life for selected Rare Diseases	Malattie rare Area C	Istituto Superiore di Sanita'		656.600,00	409.600,00	0	49
39	RF-ISS-2008-1249718	Identification of new mild hemophiliacs in the Italian young population: a pilot study assessing bleeding history in the schools	Malattie rare Area C	Istituto Superiore di Sanita'		267.700,00	155.700,00	0	47,33
40	RF-INN-2008-1294709	SOCIAL AND ECONOMIC COSTS FOR FAMILIES DUE TO RARE DISEASES (RADICES)	Malattie rare Area C	CARLO BESTA		586.300,00	415.520,00	10000	44
41	RF-CAM-2008-1223767	"Rare diseases: model to improve both diagnostics and health service both the life quality of the affected citizens from rare diseases"	Malattie rare Area C	Campania		0,00	0,00	0	30,67
42	RF-FGB-2008-1285119	EPIDEMIOLOGY OF KERATOCONUS IN ROME AND IN ITALY, THE FIRST EPIDEMIOLOGIC REGISTRY OF A OCULAR PATHOLOGY	Malattie rare Area C	BIETTI		370.000,00	370.000,00	0	22,33