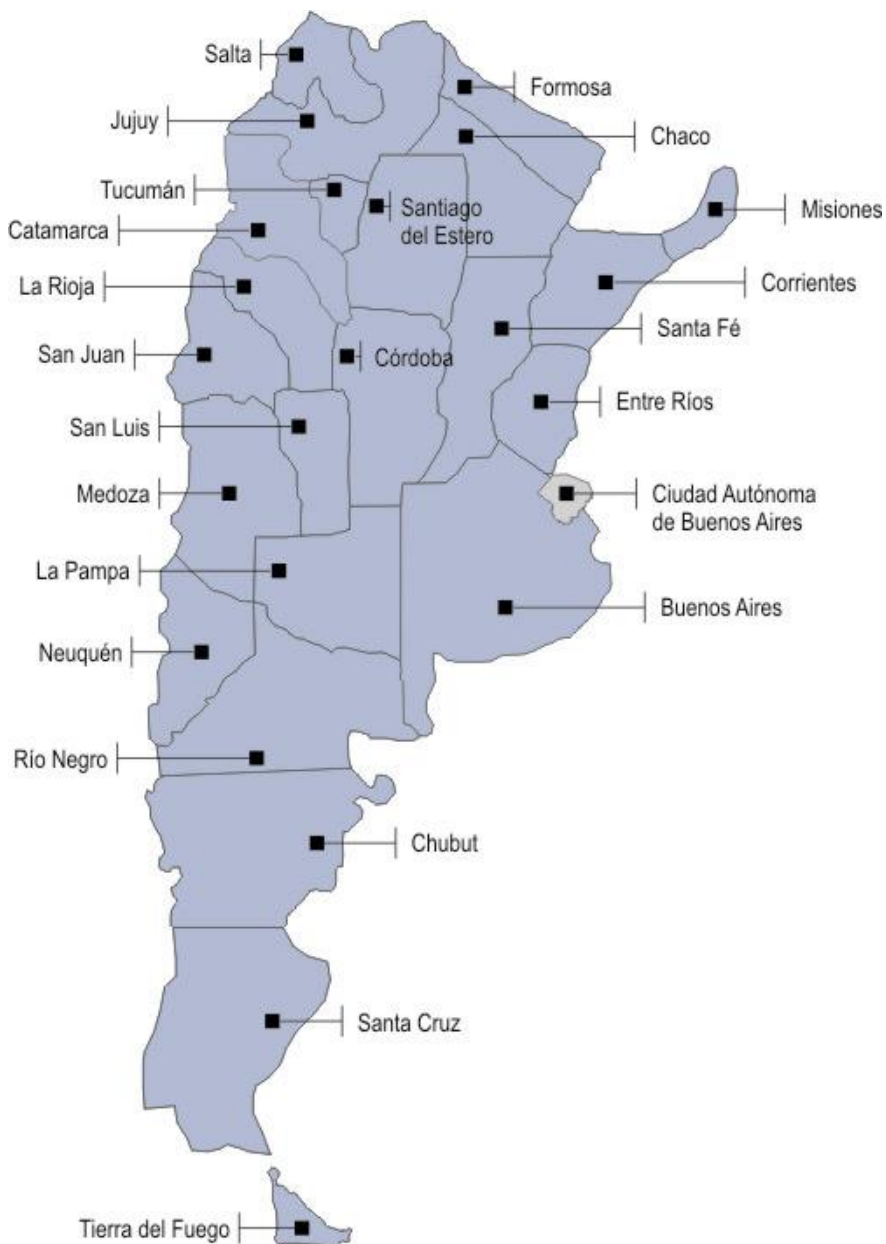


# National System of Procurement and Transplantation in Argentina

July - 2007



# National System of Procurement and Transplantation in Argentina



## Argentina

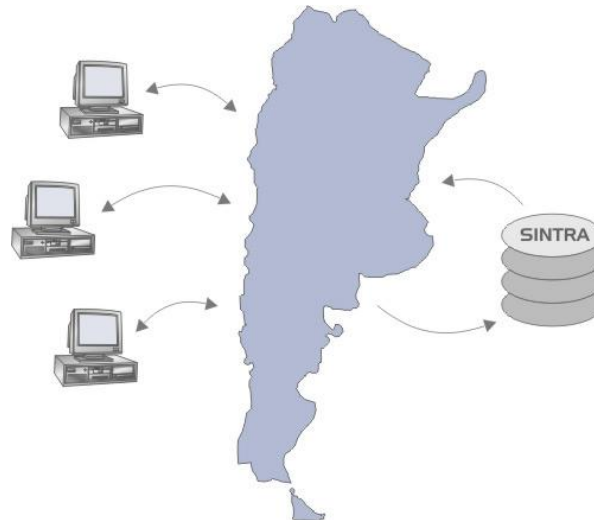
- ◆ Population: 39 million inhabitants
- ◆ Surface: 2.791.810 Km<sup>2</sup>
- ◆ The country is divided into 24 provinces and Buenos Aires City
- ◆ INCUCAI, decentralized organism depending on the National Health Ministry -created by National Law N° 24.193-, is the national authority that coordinates organ, tissue and cell procurement and transplantation.
- ◆ Rate of donors 2006: 11.7 PMP (per million population)

## SINTRA

- ◆ SINTRA is the online database system that administrates, manages and supervises organ, tissue and cell procurement and transplantation activities in the national field.
- ◆ A project impelled, coordinated and financed by INCUCAI, that started in 2003 and still continues its development.

## Main strategy

- ◆ **To decentralize information management**, in order to empower all the actors that take part in the different processes by interacting directly with SINTRA, and to **centralize information in an unique database**, integrated and consolidated.



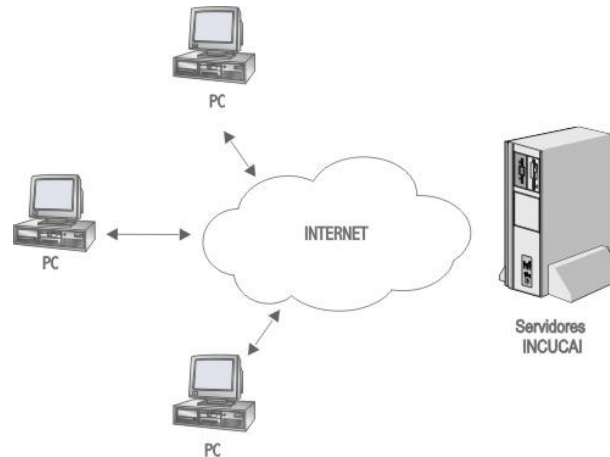
## Main objectives

- ◆ **APPLY THE REGULATORY FRAMEWORK**  
To implement all the regulations established by INCUCAI policies through computer based procedures that guarantee their accomplishment.
- ◆ **REGISTRY**  
To create and keep updated national registries related to procurement and transplant activity, assuring the protection of personal information as is stated by Law of Habeas Data N° 25.326.
- ◆ **TRACEABILITY**  
To allow **traceability** across every process from donor to recipient and vice versa, assuring confidentiality and different access to information.
- ◆ **ASSESSMENT**  
To provide regional authority, INCUCAI and other health organizations with a tool that enables them to monitor and audit related activities.
- ◆ **MANAGEMENT CONTROL**  
To provide health authorities and professional community with a tool that enables them to evaluate and analyze different aspects of the procurement and transplant activity, aiming to help in the decision making process concerning health policies or clinical research.
- ◆ **TRANSPARENCY**  
To offer society a guarantee of transparency of the activity, allowing access and information availability with several levels of complexity, in order to satisfy different requirements.

## Technical features

### ◆ WEB TECHNOLOGY BASED APPLICATION

Internet access. The connection service is determining.



### ◆ HIGH AVAILABILITY

SINTRA is working 24 hours a day, 365 days a year.

### ◆ RELIABLE AND SECURE

It has been developed with confident and strong technologies: RHEL, Oracle, J2EE. Its design emphasizes information confidence and security, and all necessary measures to assure that are taken. For instance, authentication access with user passwords and implementation of secure session (information exchanged between the computer connected to the system and INCUCAI servers is codified to avoid its alteration or inspection)



## Technology architecture

- ◆ **Own staff, development, maintenance and administration**
- ◆ **Own data center with:**
  - ◆ Redundant automated air conditioning system to guarantee temperature and humidity
  - ◆ Redundant electrical system for uninterrupted power supply
  - ◆ High availability hardware architecture x86: HP DL 380, IBM xSeries 336 y 345
  - ◆ Software platforms: RHEL, Oracle 10g, J2EE

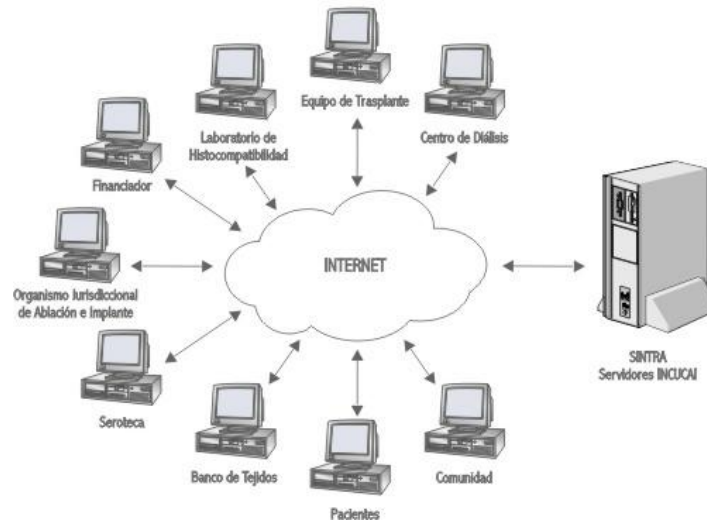
## Modules

SINTRA is divided into 6 modules and a statistics and reports center. Each module has its own group of users and its particular functionality, but they are all related and connected in a great database.

- ◆ **Module 1:** National Registry of Chronic Renal Failure Patients (patients on dialysis)  
<http://irct.incucai.gov.ar> (ongoing since January 2004)
- ◆ **Module 2:** National Registry of Patients in Organ and Tissue Waiting List  
<http://le.incucai.gov.ar> (ongoing since July 2005)
- ◆ **Module 3:** National Registry of Procurement Activity (organ and tissue donors)  
<http://procura.incucai.gov.ar> (ongoing since July 2005)
- ◆ **Module 4:** National Registry of Transplantation  
<http://procura.incucai.gov.ar> (ongoing since July 2005)
- ◆ **Module 5:** National Registry of Voluntary Expressions about Donation  
<http://donar.incucai.gov.ar> (ongoing since April 2003)
- ◆ **Module 6:** National Registry of Bone Marrow Donors  
<http://cph.incucai.gov.ar> (ongoing since June 2003)
- ◆ **CRESI:** SINTRA Statistics and Reports Center  
<http://cresi.incucai.gov.ar> (ongoing since July 2005)

## SINTRA users

User	Quantity	SINTRA Connections (July 05 / June 07)	Used modules					
			1	2	3	4	5	6
INCUCAI:	1	60574	X	X	X	X	X	X
Regional procurement organizations:	24	190718	X	X	X	X	X	
Dialysis centers:	464	293290	X	X				
Organ transplant teams:	119	123076		X	X	X		
Tissue transplant teams:	219			X	X	X		
Histocompatibility laboratories:	29	317	X					
Tissue banks:	52	5633	X	X				
Tissue type serum samples storage:	12	2931	X					
Health insurances:	139	17780	X					
<b>Total users:</b>	<b>1059</b>	<b>699319</b>						
<b>Patients' access accounts:</b>	<b>15288</b>	<b>19575</b>	X	X				



## Module 1: National Registry of Chronic Renal Failure Patients (patients on dialysis) MAIN COMPONENTS

ID	Nombre	CP	Provincia	Registro	Situación
8002	PAC ARGENTINA SA - ECORSA	1608	BUENOS AIRES	CD	13/01/04 ACTIVO
8003	HOSPITAL NACIONAL DE NEFROLOGIA	1608	BUENOS AIRES	CD	13/01/04 ACTIVO
8004	HOSPITAL NACIONAL PROF. A. FIDELAZZI	1608	BUENOS AIRES	CD	13/01/04 ACTIVO
8005	PAC ARGENTINA S.A. - CIUDADDELA	1700	BUENOS AIRES	CD	13/01/04 ACTIVO
8006	HOSP. PROF. DR. LUIS SUJANES - SERVICIO DE NEFROLOGIA	1708	BUENOS AIRES	CD	13/01/04 ACTIVO
8007	CEREP	1754	BUENOS AIRES	CD	14/01/04 ACTIVO
8008	EL NEREA SRL	1808	BUENOS AIRES	CD	14/01/04 ACTIVO
8009	CENTRO NEFROLOGICO PAM	1808	BUENOS AIRES	CD	14/01/04 ACTIVO
8010	HOSPITAL GENERAL	1916	BUENOS AIRES	CD	14/01/04 ACTIVO
8011	MAR S.T.E.H. TEMPLELEY SA	1916	BUENOS AIRES	CD	14/01/04 ACTIVO
8012	FRENTE MEDICAL CARE S.A. URBAN	1916	BUENOS AIRES	CD	14/01/04 ACTIVO
8013	FRENTE MEDICAL CARE ARGENTINA SA. SECTO LINDAS	1916	BUENOS AIRES	CD	14/01/04 ACTIVO

### National registry of dialysis centers

It registers information about structure, services and qualified staff of each center. The registration process is done online and monitored by the regional health authority.

**Formulario 02-ORI Ingreso de paciente a diálisis**  
JEJUS PABLO O NERIO, DM 5482722 (solo lectura)

Director médico: DANIEL NICOLAS MANZOR  
Especialización: 03/03/2004 14:03

Fiscalía: SILVIA EDITH FERNANDEZ  
Organismo: CCABA  
Confirmación: 13/03/2004 20:40

Centro de diálisis	Paciente	Dominio	Financiador	Primer tratamiento	Modalidad
Acceso vascular	Comorbilidad	Riesgo infebiológico	Laboratorio	Serología	Estudios
Capacidad funcional	Situación laboral	Situación social			

Centro de diálisis: Nombre: NEFROLOGIA AVELLANEDA S.A., Provincia: BUENOS AIRES, Número de registro: 18271, Médico a cargo del paciente: OSCAR FERRARO, Director médico responsable: DANIEL NICOLAS MANZOR, Fecha de confección ORI: 03/03/2004

### National registry of patients on chronic dialysis

Whenever a patient starts dialysis, there is registered medical information about treatment, clinical evaluation, laboratory, infectious profile, comorbidity, social and work situation, functional ability, type of dialysis, infectious risk, treatment health insurance, personal information of the patient. All data is monitored and audited by the regional health authority.

**PEDRO IMPERI, DNI 3241141 (PAC # 143501)**  
Fecha personal

Acciones que Usted puede realizar

Datos personales y domicilio del paciente  
Situación actual del tratamiento de diálisis  
Notas y comentarios

Secciones de la ficha del paciente  
LABORATORIO, SEROLOGIA Y ESTUDIOS COMP

ID	Tipo	PROBARR	Centro de diálisis	Efectivizado	Situación
201378	EST	67209	FRENTE MEDICAL CARE ARGENTINA SA - FLORIDA	16/11/00 16:11	CONFIRMADO
201378	SEN	67209	FRENTE MEDICAL CARE ARGENTINA SA - FLORIDA	16/11/00 16:11	CONFIRMADO
201377	LAB	67209	FRENTE MEDICAL CARE ARGENTINA SA - FLORIDA	16/11/00 16:11	CONFIRMADO
201325	EST	68980	CERINOR PRIVADO SRL	26/09/00 16:25	INACTIVO
201324	SEN	68980	CERINOR PRIVADO SRL	26/09/00 16:25	INACTIVO
201323	LAB	68980	CERINOR PRIVADO SRL	26/09/00 16:25	INACTIVO

### Patient personal record

The patient personal record centralizes all information about dialysis treatment. It includes all time periods receiving dialysis in different centers and updated medical records, and also his situation in national waiting list.

## Module 2: National Registry of Patients in Organ and Tissue Waiting List

### MAIN COMPONENTS

Equipo de trasplante y pacientes en lista de espera

#ETX Programa	Instalación	Provincia	Adu/Ped Gestión	Vigencia	Situación
988	CORONA Y ESCILERA DOCTOR LUCIO MELUCCI	LA PAMPA	SI / SI	ETX 18.06.2007 08:00	HABILITADO
987	CORONA Y ESCILERA DR. JOSE CESAR PERAZZO	SANCS	SI / SI	ETX 02.04.2007 08:00	DESINABILITADO
1100	CORONA Y ESCILERA HOSPITAL DE PEDIATRIA JUAN P. GARIBAY	CAPITAL FEDERAL	NO / SI	ETX 24.06.2007 08:00	HABILITADO
604	CORONA Y ESCILERA HOSPITAL CENTRAL	MENDOZA	SI / SI	ETX 06.06.2007 08:00	HABILITACION EN TRAMITE
989	CORONA Y ESCILERA DR. JOSE MARIA CYLON	SANTA FE	SI / NO	ETX 01.05.2007 08:00	DESINABILITADO
607	CORONA Y ESCILERA HOSPITAL DE CLINICA JOSE DE SAN CARLOS MARTIN	CAPITAL FEDERAL	SI / SI	ETX 21.06.2007 08:00	HABILITADO
401	CORONA Y ESCILERA LABORATORIO PARQUE	TUCUMAN	SI / SI	ETX 01.06.2007 08:00	HABILITADO

### National registry of procurement organizations, transplant teams, tissue banks and histocompatibility laboratories

It registers information about structure, services and qualified staff of each center. The registration process is done online and monitored by the regional health authority.

Ficha de inscripción en lista de espera HEPÁTICA

Situación del proceso de inscripción

Lista de espera: HEPÁTICA

Fecha de inscripción: 15-06-2007 18:09

Situación clínica: PUNTAJE MELD/PELD / PUNTAJE MELD/PELD

Método de inscripción: SIMPLIFICADO

INCALCIZADO Paso 1 - INDICACION DE EVALUACION PRE-TRASPLANTE

Fecha de indicación: 15-06-2007 18:09

Responsable: MIGUEL ANGEL CIARDULLO

Responsable: CARLOS MANES

INCALCIZADO Paso 2 - AUTORIZACION DE FINANCIAMIENTO PARA LA EVALUACION PRE-TRASPLANTE

Fecha de autorización: 15-06-2007 18:02

Responsable: SIN ESPECIFICAR

Responsable: CARLOS MANES

INCALCIZADO Paso 3 - EVALUACION PRE-TRASPLANTE

Fecha de evaluación: 15-06-2007 18:08

### Process of registration in the waiting list

There are 15 lists. Each of them has its own registration process which contains the following steps: medical professional that diagnoses the need of a transplant, the health insurance that covers it, the laboratory that makes immunology evaluation. All process is done online and can be monitored by the patient himself, who gets his access account password when the registration begins. Kidney waiting list is linked to national dialysis register.

HUMBERTO MAXIMO BURGOS DNI 12081539

Ficha personal del potencial receptor #94112

Acciones que usted puede realizar

Situación en lista de espera del potencial receptor

BAJA TRANSITORIA de lista de espera HEPÁTICA por TRASPLANTE CON DONANTE CADAVÉRICO. FUNDACION AUZIL ORO ETX #2713; Habilitación ok. Sin TX. OROA ERM 11/02/05.

INSCRIPCIONES EN LISTA DE ESPERA

ETX	LE	Indicacion	Via. Adm.	Evaluacion	Inscrito	Método	Situación LE
98789	HEPATICA	15-06-2007 18:09	15-06-2007 18:02	15-06-2007 18:08	15-06-2007 18:09	SIMPLIFICADO	BAJA TRANSITORIA
20401	HEPATICA	15-06-2007 18:09	15-06-2007 18:02	15-06-2007 18:08	15-06-2007 18:09	NORMAL	BAJA TRANSITORIA

Movimientos

#MOV	LE	Movimiento	Motivo principal	Responsable	Fecha	Confirmado	Situación
20401	HEPATICA	TRASPLANTE CON DONANTE CADAVÉRICO	ENTRA INCUCA	15.06.2007 18:09	15.06.2007 21:03	CONFIRMADO	CONFIRMADO
20402	HEPATICA	TRASPLANTE CON DONANTE CADAVÉRICO	ENTRA INCUCA	14.07.2008 12:30	14.07.2008 12:30	CONFIRMADO	CONFIRMADO

### Patient personal record

The patient personal record centralizes all information since the need of a transplant is diagnosed. It includes the period in the waiting list, the organ or tissue transplant itself and the follow up. It contains all exams done by the different transplant centers visited by the patient, all the registration processes, and the updates of all his clinical evaluations and personal information, as well as his participation in organ or tissue distribution process and his dialysis record (if applied).

## Module 3: National Registry of Procurement Activity (organ and tissue donors)

### MAIN COMPONENTS

**Equipos de trasplante y pacientes en lista de espera**

#ETX Programa	Institución	Provincia	Adu/Fred Creación Vigencia	Situación
1180	SISTEMAS COLGABOLETICO Y SISTEMATUCULAR HOSPITAL ANITA FREIDMAN - SIDA REINA	RIO NEGRO	01/10 071	28-10-2007 00:00 HABILITADO
1189	SISTEMAS COLGABOLETICO Y SISTEMATUCULAR HOSPITAL DR. HORACIO NELLER	MENDOZA	01/10 071	28-10-2007 00:00 HABILITADO
1190	SISTEMAS COLGABOLETICO Y SISTEMATUCULAR LABORATORIO DE LOS ANDES	CAPITAL FEDERAL	01/10 071	28-10-2007 00:00 HABILITADO
204	SISTEMAS COLGABOLETICO Y SISTEMATUCULAR LABORATORIO SAN JOSE	CAPITAL FEDERAL	01/10 071	28-10-2007 00:00 DESHABILITADO
300	SISTEMAS COLGABOLETICO Y SISTEMATUCULAR HOSPITAL GENERAL DE NUEVO PAMPEIRO PERAZA	CAPITAL FEDERAL	01/10 071	28-10-2007 00:00 HABILITADO
308	SISTEMAS COLGABOLETICO Y SISTEMATUCULAR LABORATORIO MESSOLIA S.A.	MISIONES	01/10 071	28-10-2007 00:00 HABILITADO
363	SISTEMAS COLGABOLETICO Y SISTEMATUCULAR UT LABORATORIO INTENSIV	MISIONES	01/10 071	28-10-2007 00:00 HABILITADO

### National registry of institutions generating donors, procurement teams and transplant coordinators

It registers information about structure, services and qualified staff of each center. The registration process is done online and monitored by the regional health authority.

**Proceso de donación #409051 (ABIERTO)**

Donación: CORNEO CUCABOLETICO - PROCESO EN EJECUCION

Procesos de distribución:

- LISTA PARA DISTRIBUCION RENAL
- LISTA PARA DISTRIBUCION PANCREATICA
- LISTA PARA DISTRIBUCION RENOPANCREATICA
- LISTA PARA DISTRIBUCION INTESTINAL
- LISTA PARA DISTRIBUCION CORNEAL

ID	Resolución	Inicio	Cierre	Responsable	FE/Alarg	En Fila	Situación
60400	CORNEO	07/08/2007 00:00	07/08/2007 00:00	TRONCOSO JUAN CARLOS	00000000	ABIERTO	EN EJECUCION
60401	INTRATHORACICA	07/08/2007 00:00	07/08/2007 00:00	RODRIGUEZ ANTONIO	00000000	ABIERTO	EN EJECUCION
60402	INTESTINAL	07/08/2007 00:00	07/08/2007 00:00	TRAILLALUCAS	00000000	ABIERTO	EN EJECUCION
60403	RENOPANCREATICA	07/08/2007 00:00	07/08/2007 00:00	TRAILLALUCAS	00000000	ABIERTO	EN EJECUCION
60404	INTRATHORACICA	07/08/2007 00:00	07/08/2007 00:00	RODRIGUEZ ANTONIO	00000000	ABIERTO	EN EJECUCION
60405	HEPATICA	07/08/2007 00:00	07/08/2007 00:00	TRAILLALUCAS	00000000	ABIERTO	EN EJECUCION

### National registry of procurement activity: donation process

Donation process by cadaveric donor is the basis of the national registry of organ and tissue procurement. It begins with potential donor detection in a health center and ends when the organ and tissue distribution and allocation process is closed. It includes death diagnose, eligible death evaluation for organ or tissue donation, family interview, legal authorization, distribution and allocation process and recovery and transplant records.

**LISTA PARA DISTRIBUCION RENAL #604393**

Situación de la lista: EN EJECUCION

FCF: 409051

Organos: RN / TRANSPLANTADO

Edad: 40-60 años

Grupos: B

HCA: A27 / B31 / A9 / DR13 / T4

Talla: 170 cm

Medidas: A3 02/01/104/JUN/04/ES/25

Fili: ARGENTINA

Región: LETICIA

Provincia: MISIONES

Comentarios: A1 2-----AD-----B1135-PR-----B2-9-8-21-----DB115-6-----BR2-----

#LISTA Orden Paciente	Equipo de trasplante	UF /NH/2N/3C Lista	Alargue	Situación OT
60400	RENAL	CUNCA DE NEFROLOGIA UNIDAD 1 (SISTEMAS COLGABOLETICO Y SISTEMATUCULAR)	PROVINCIA NO	IMPLANTADO
60401	RENAL	CUNCA DE NEFROLOGIA UNIDAD 1 (SISTEMAS COLGABOLETICO Y SISTEMATUCULAR)	PROVINCIA NO	IMPLANTADO
60402	RENAL	CUNCA DE NEFROLOGIA UNIDAD 1 (SISTEMAS COLGABOLETICO Y SISTEMATUCULAR)	PROVINCIA NO	IMPLANTADO

### Distribution and allocation process

There are 7 distribution and allocation processes: RENAL, LIVER, INTRATHORACIC, PANCREATIC, RENOPANCREATIC, INTESTINAL and CORNEAL. Each of them has its own policy (INCUCA policies) stating proper rules and medical and geographic criteria that create the order of the list of potential recipients, whenever it is necessary to distribute and allocate an organ or tissue. The distribution and allocation process is closely related to waiting lists.

## Module 4: National Registry of Transplantation

### MAIN COMPONENTS

**INCUCAI** SISTEMA NACIONAL DE INFORMACIONES DE REGISTRO Y TRANSPLANTE DE LA REPUBLICA ARGENTINA  
Registro Nacional de Procurement y Transplante

**Certificado de ablación #25906**

Completado: ANIELLA DIAMELLI / CUCARBA CRAI NORTE / Fecha: 11-06-2007 10:30

Fiscalización: ROBERTO PESIET / BUENOS AIRES TRASPLANTE / Fecha: 12-06-2007 10:30

Proceso de donación #: 486491  
Establecimiento origen: HOSPITAL GRAL. DE AGUIROS CARLOS G. DURAND (EXT #30033)  
Provincia / Organismo responsable: CAPITAL FEDERAL / BUENOS AIRES TRASPLANTE  
Donante: ANIELLA DIAMELLI  
Instituto / sexo / edad: H / MASCULINO / 49,45 años  
Documento: DNI 12943827  
Organo/Tajido: HIGADO  
Destino: IMPLANTE  
Certificado de implante1 #: 43641  
Certificado de implante2 #:  
Institución que ablación: CUCARBA CRAI NORTE  
Número de institución / Provincia: 38595 / BUENOS AIRES  
Número de ETK / Programa: 534 / HIGADO  
Médico responsable: LORENZO TEODORO TONELLI  
Fecha de clampo: 10-06-2007 05:35  
Solución de preservación: HTE  
Contancia de fiscalización CSO: 398876

### National registry of transplantation: transplant certificate (TC)

The transplant certificate (TC) is the basis of the National Registry of Transplantation. Each TC is originated in a donation process and is always automatically created when monitoring the donation process. It is completed by the transplant center and monitored by the regional health authority or INCUCAI.

**INCUCAI** SISTEMA NACIONAL DE INFORMACIONES DE REGISTRO Y TRANSPLANTE DE LA REPUBLICA ARGENTINA  
Listado de Esporas de Organos y Tejidos

**Proceso de donación con donante vivo RENAL #1020**

Fecha de inscripción en lista de espera: 00/00/00  
Completado: ALFREDO MARIO INTROZZI / Fecha: 07-06-2007 19:40

Potencial donante | Evaluación pretrasplante | Transplante | Certificado de ablación e implante

**FORMULARIO 40-9D - PROCESO DE DONACIÓN CON DONANTE VIVO (Remoldear este formulario)**

Completó el formulario 40-9D: ALFREDO MARIO INTROZZI  
Responsable de la evaluación pretrasplante: ALFREDO MARIO INTROZZI  
Institución: HOSPITAL PRIVADO DE LA COMUNIDAD - HAR DEL PLATA (EXT# 523)  
Fecha de última actualización: 07-06-2007 19:40

Fiscalización: -sin dato-  
Organismo: -sin dato-  
Fecha de fiscalización: -sin dato-  
Contancia de fiscalización CAD:

Resultado de la evaluación: **APTO PARA SER DONANTE**  
Filiación: ESPOSD (relación del donante con el receptor)  
Peso (kg): 65  
Talla (cm): 160  
Creatinina sérica (mg/dl): 1  
TA sistólica (mm/Hg): 118  
TA diastólica (mm/Hg): 78

### Donation process from living donor

The donation process from living donor, together with the donation process from cadaveric donor, is the basis of the National registry of organ and tissue procurement and transplantation. It begins with the registration of a patient in the national waiting list and ends once the transplant is done. It includes clinical evaluation before the transplant, informed consent, transplant data and recovery and transplant certificates. It is carried out by the transplant team and monitored by the regional authority on procurement and transplantation.

**INCUCAI** SISTEMA NACIONAL DE INFORMACIONES DE REGISTRO Y TRANSPLANTE DE LA REPUBLICA ARGENTINA  
Listado de Esporas de Organos y Tejidos

**Seguimiento inmediato de trasplante hepático (SIT) #1005**

Fecha personal del receptor #154879  
Organismo responsable: CUCARBA

Completado: MARTHA CASNOLI / CUCARBA CRAI NORTE / Fecha: 07-06-2007 11:48

General | Estudios y Exámenes | Esporas de Inmunosupresión

**FORMULARIO 65-LE - SEGUIMIENTO INMEDIATO DE TRASPLANTE (Remoldear este formulario - \* Este es obligatorio)**

Número de SIT: 1005  
Número de inscripción en LE: 243351  
Número de CID / Número de FID: 43361 / 484565  
Receptor / Documento: PAEZ ADRIANA / DNI 26708106  
Fecha de desclamping del Tr: 09-06-2007 04:00  
Centro de trasplante: CUCARBA CRAI NORTE  
Nro. de ETK / Programa de Tr: 534 / HIGADO  
Organo implantado: HIGADO  
Fecha de creación del SIT: 06-06-2007 10:18  
Centro de seguimiento: CUCARBA CRAI NORTE  
Nro. de ETK / Programa de Tr: 534 / HIGADO  
Médico responsable del SIT: -sin dato-

Domicilio del potencial receptor:  
Calle: ESQUEL Nro: 2733 Piso: -sin dato- Opto: -sin dato-  
Provincia: BUENOS AIRES

### Posttransplant follow up

Each transplant done begins a posttrasplant follow up in order to know about the organ or tissue and recipient's outcome. There are two forms for follow up: one of immediate transplant follow up (ITF) to be completed only once, 30 days after the transplant; and one of annual transplant follow up (ATF), to be completed every year. Both ITF and ATF include personal information of the recipient, posttransplant health insurance, and survival data of organ or tissue and recipient posttransplant adverse events and immunosuppressive treatment. Follow up is completed by transplant center and monitored by the corresponding regional health authority.

## Module 5: National Registry of Voluntary Expressions about Donation

### MAIN COMPONENTS

The screenshot shows the 'Acta de manifestación expresa de voluntad de donación de órganos y tejidos' form. It includes fields for 'Tipo de documento', 'Apellido', 'Nombre', 'Sexo', 'Fecha nacimiento', 'Estado civil', 'Calle', 'Provincia', and 'Buscar localidades'. The form is titled 'Registro Nacional de Expresiones de Voluntad para la Donación'.

### National registry of voluntary expressions about donation

This registry allows the citizens to record their personal decision about organ and tissue donation, which can be positive or negative. There are several ways of joining this register: in the Civil Register offices, when getting the personal ID, by telegram and in the regional procurement and transplant organizations, among others.

## Module 6: National Registry of Bone Marrow Donors

### MAIN COMPONENTS

The screenshot shows a table of bone marrow donors. The table has columns for 'Código Apellido', 'Nombre', 'Documento', 'Captación Previa', and 'Situación'. The data is as follows:

Código Apellido	Nombre	Documento	Captación Previa	Situación
00008	SONDALE EDUARDO HERMANO	DM 1752281 16840300	BUENOS AIRES	NO TIPIFICADO
00014	SONDALE CRISTINA LUCIA LORENZ	DM 2522096 16840300	BUENOS AIRES	NO TIPIFICADO
00047	SONDALE PEDRO THOMAS	DM 1182141 16840300	BUENOS AIRES	NO TIPIFICADO
00091	SONDALE JOSIE LUIS	DM 2084024 16840300	CAPITAL FEDERAL	NO TIPIFICADO
00495	SONDALE MARCELO JOSE	DM 1786142 16840300	CAPITAL FEDERAL	NO TIPIFICADO
00446	SONDALE CHIFFRE PABLO	DM 1296761 21850300	CAPITAL FEDERAL	NO TIPIFICADO
00603	SONDALE KARINA ALEJANDRA	DM 2610734 21850300	CAPITAL FEDERAL	NO TIPIFICADO
00023	SONDALE ANITA BEATRIZ	DM 4217612 16840300	BUENOS AIRES	NO TIPIFICADO
00062	SONDALE MARCELO JUAN CARLOS	DM 1674244 16840300	BUENOS AIRES	NO TIPIFICADO
00014	SONDALE DAVID JUAN CARLOS	DM 2639413 22850300	CAPITAL FEDERAL	NO TIPIFICADO
00017	SONDALE RAUL ALFREDO	DM 1681170 16840300	BUENOS AIRES	NO TIPIFICADO
00068	SONDALE GUSTAVO CARLOS	DM 1280518 16840300	BUENOS AIRES	NO TIPIFICADO

### National registry of bone marrow donors

This registry is composed by those citizens that propose themselves as bone marrow donors and accomplish all the necessary medical requirements. The national bone marrow donors registry is only managed by INCUCAI.

## CRESI: SINTRA Statistics and Reports Center

### INTRODUCTION



The screenshot shows the CRESI website interface. At the top, there is a header with the SINTRA logo and the text 'Sistema Nacional de Información SINTRA' and 'Instituto Nacional Central Único Coordinador de Ablación e Implante INCUCAI'. Below the header, there is a navigation bar with the text 'SISTEMA NACIONAL DE INFORMACIÓN DE PROCURACIÓN Y TRASPLANTE DE LA REPUBLICA ARGENTINA Central de Reportes y Estadísticas - CRESI'. The main content area contains a welcome message: 'Bienvenido al CRESI, la Central de Reportes y Estadísticas del SINTRA. Aquí Usted podrá obtener toda la información relacionada con la actividad de procuración y trasplante en el ámbito nacional. El CRESI integra los 6 Módulos del SINTRA y cuenta con reportes flexibles y dinámicos que le permiten obtener información en tiempo real. Leer más acerca del CRESI...'. Below the welcome message, there is a dropdown menu labeled 'Iniciar sesión para usar el cresi en: -módulo-' with a downward arrow. The main content area is divided into several sections, each with a title and a brief description:

- Documentación**: Aquí podrá obtener documentación acerca de la legislación vigente, leyes nacionales y decretos reglamentarios, resoluciones del Ministerio de Salud y Ambiente y del Directorio del INCUCAI, formularios PDF y Manuales de Usuario entre otros.
- Instituciones y profesionales**: Aquí podrá consultar instituciones habilitadas para trasplante, bancos de tejidos, laboratorios, centros de diálisis, establecimientos asistenciales, financiadores, serotecas y organismos jurisdicciones entre otros, con sus respectivos profesionales asociados.
- Pacientes en diálisis**: Aquí podrá consultar el Registro Nacional de Insuficiencia Renal Crónica Terminal (IRCT) y obtener información acerca de los pacientes en diálisis en centros de la República Argentina.
- Situación en lista de espera de pacientes en diálisis**: Aquí podrá consultar información acerca de la situación en lista de espera de los pacientes en diálisis. Esta sección relaciona el Registro Nacional de IRCT con las Listas de Espera de Organos y Tejidos y sus indicadores más relevantes.
- Listas de espera de órganos y tejidos**: Aquí podrá consultar información acerca de las listas de espera de órganos y tejidos, podrá consultar pacientes inscriptos y en proceso de inscripción, exclusiones transitorias o permanentes y la lista nacional de emergencias y urgencias entre otros reportes.
- Registro nacional de procuración y trasplante**: Aquí podrá consultar información acerca de la actividad de procuración y trasplante en el ámbito nacional, incluyendo indicadores relevantes, cuadros comparativos y curvas de proyección entre otros reportes.
- Registro nacional de expresiones de voluntad para la donación**: Aquí podrá consultar el Registro Nacional de Expresiones de Voluntad para la Donación (RENADON) y saber si está registrada su expresión de voluntad o consultar centros de donación entre otros reportes.
- Registro Nacional de donantes de células progenitoras hematopoyéticas**: Aquí podrá consultar el Registro Nacional de células progenitoras hematopoyéticas (CPH) y saber si está registrado como donante o consultar centros de donación entre otros reportes.

CRESI allows the user to find all the information related to national procurement and transplantation activity. CRESI integrates the 6 SINTRA modules and provides flexible and dynamic reports with information obtained in real time.

CRESI itself is organized in 8 general sections, each of which contains available reports grouped in displaying menus, with hierarchical levels of visualization. The first section provides documentation which can be downloaded to the user's computer.

<http://cresi.incucai.gov.ar>

SINTRA follows the rules established by the Law of Protection of Personal Information N° 25.326, Law of Habeas Data: Keeping confidentiality and medical secret of the personal details of potential donors, recipients and professionals; having the technical resources that guarantee the necessary security and confidentiality; and allowing the access to professionals and family members of the potential donors and recipients to search and update the personal information.

## CRESI: SINTRA Statistics and Reports Center SIGNIFICANT COMPONENTS



### Flexible and dynamic information in real time

There are hundreds of available reports. All of them allow the user to apply selected variables in order to narrow the evaluated population and to select multiple criteria of delivery. Most of the reports are of public access and those more specific are kept only for the registered users.

### Click&graphic: Graphics in real time

The function click&graphic allows to create a graphic in real time, on the basis of a line or column of a generated report. It is easy to create a graphic, since the user only has to click the selected line or column. This function has public access.



### Click&list: Access to data in real time

The function click&list allows to know the data of a cell of a generated report. It is easy to create a list, since the user only has to click the selected cell of the report. This function is kept for registered users.

ID	PPD	Potencial donante	Establecimiento	Provincia	Registro	Situación
10016	4617	ALFONSO 18.00	DR. ROBERTO NOTTE	MENDOZA	11.08.2007 14.50	DE DONANTE DE TEJIDOS
10476	4618	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10478	4619	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10479	4620	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10480	4621	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10481	4622	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10482	4623	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10483	4624	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10484	4625	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10485	4626	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10486	4627	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10487	4628	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10488	4629	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10489	4630	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10490	4631	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10491	4632	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10492	4633	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10493	4634	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10494	4635	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10495	4636	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10496	4637	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10497	4638	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10498	4639	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10499	4640	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS
10500	4641	PAZ FANCIOLANO 13.07	HOSPITAL DR. GUILLERMO RAMON	SAN JUAN	04.08.2007 10.37	DE DONANTE DE TEJIDOS

## Automation

- ◆ SINTRA embodies multiple automations and validations that guarantee information integrity and consistency along all the registries. Those integrity and functionality rules are applied during the processes execution and are recorded in tables for further monitoring.

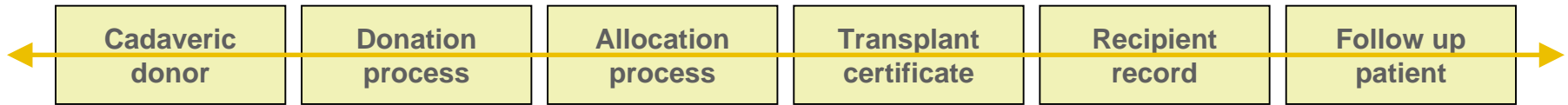
## Usage

◆ SINTRA is an online database system that has overcome the planned expectations and goals. From its implementation on, with a great national coaching effort, it has reached great adherence of its users and the following quantified results:

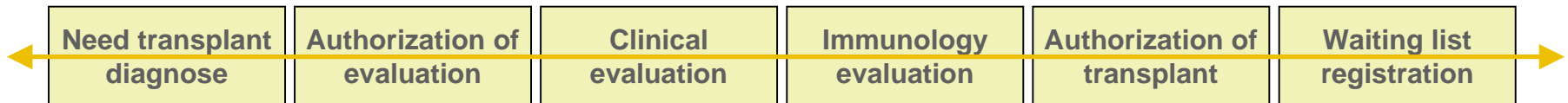
- ◆ **24472 Patients on dialysis**
- ◆ **7719 Patients in waiting list**
- ◆ **7237 Donation processes**
- ◆ **4597 Organ and tissue distribution and allocation processes**
- ◆ **10049 Recovery and transplant certificates**
- ◆ **24159 Voluntary bone marrow donors registry**
- ◆ **2223276 Voluntary expressions about organ donation**
- ◆ **417893 Delivered certificates**
- ◆ **718894 SINTRA connections**

## Traceability

SINTRA allows traceability along all its processes. An example that can be given is the one of 'donor-recipient', as it is shown in the following scheme:



Another example is the one of 'process of registration in the waiting list':



## Transparency

SINTRA is a system that guarantees transparency along all its processes.

- ◆ In order to achieve transparency, the following characteristics have been applied:
  - ◆ **Registry of internal auditory containing all the data changes made**
  - ◆ **Registry of historic information, always available**
  - ◆ **Available information in the screen, that enables the user to make a deduction of what has happened**
  - ◆ **Impossibility of modifying or altering information on the outside of SINTRA**
  - ◆ **A statistics and reports center that enables population to search for the proper information to evaluate the activity with a high level of detail**

## Results

- ◆ SINTRA has helped to:
  - ◆ **Control and monitor activities in INCUCAI and in the regional procurement and transplantation organizations**
  - ◆ **Allow management control. Since SINTRA has been implemented, several situations have been identified. Their detection is done through the monitoring tools and CRESI. As a result, correcting measurements have been applied.**
  - ◆ **Make scientific analysis or clinical research**
  - ◆ **Provide a wider information availability for its users**
  - ◆ **Accomplish traceability in different processes**
  - ◆ **Guarantee the transparency of the activity**

## Continuous growing

- ◆ SINTRA is a long term investment project. Since its implementation in 2003, it grows and improves continuously. Its constant development is followed by increasing demands of new implementations. The result of this process is a continuous improvement and expansion of its different issues.

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